PERSONAL LOSS IN WELL SIBLINGS OF ADULTS WITH SERIOUS MENTAL ILLNESS:
IMPLICATIONS FOR CAREGIVING, GROWTH, AND SIBLING NEEDS

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ABSTRACT

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Using a sample of 103 well-siblings of adults with serious mental illness, the present study examined the relative contribution of well siblings’ demographic factors, reports of ill sibling illness severity levels, experiences of meaning-making coping processes (positive reappraisals, emotional processing) and personal loss in describing variation in reports of current and future caregiving, growth, and prioritization of self-care and sibling care needs. It was hypothesized that meaning-making coping and personal loss would each predict a significant portion of the variance in scores of caregiving, growth, and prioritization of sibling needs. The sample was recruited through study announcements placed on websites related to mental illness as well as through telephone and email contact with support group facilitators and leaders of chapters of the National Alliance on Mental Illness (NAMI). Five significant hierarchical regression models emerged from the data. Results of hierarchical multiple regression analyses indicate that perceived personal loss was the strongest predictor of well-siblings’ reports of current caregiving and ambivalence toward self-care and sibling needs. Results also showed that well siblings endorsement of meaning-making coping processes contributed to the prediction of stress-related growth and balance between self-care and sibling needs. Well sibling demographics (i.e., age, gender, support group affiliation) and ratings of sibling illness severity contributed to the prediction of some aspects of well sibling experiences. Findings highlight the importance of well siblings’ perceptions of personal loss due to mental illness and meaning-making coping as constructs that may have powerful implications for clinical intervention. Implications of the present study for future research and action are discussed.
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INTRODUCTION

In the fifty years since the onset of deinstitutionalization and the community care movement, the mental healthcare system in the United States has struggled to provide adequate community services for individuals coping with serious mental illness (Sartorius, Leff, Lopez-Ibor, Maj, & Okasha, 2005; Talbott, 2004). As a result, family members often represent the main source of care and support for their relatives with mental illness (Earl, 2005; Lefley & Hatfield, 1999; Lively, Friedrich & Rubinstein, 2004). In the United States, between one-third and two-thirds of persons with long-term psychiatric disabilities reside with family members (Dyck, Short, Vitaliano, 1999). Families fulfill critical roles as primary caregivers, informal case managers, and crisis intervention specialists often in the absence of training or emotional support (Marsh & Dickens, 1997). Siblings, in particular, may feel neglected by parents and mental health professionals while their ill sibling receives attention and resources. Many siblings also experience guilt over being the “healthy one” and anxiety toward present or future caregiving responsibilities (Brown, 1999).

Until fairly recently, the caregiving and support role of well siblings for their brothers or sisters with mental illness has been largely ignored (Dixon, 1997; Lukens, Thorning, & Lohrer, 2002; Marsh, 1998). Previous research suggests that, compared with parents, patterns of caregiving are more variable among siblings who are relatively free to define their relationship and the scope of their involvement with their ill sibling (Marsh & Dickens, 1997). Previous findings also suggest that well siblings vary in the degree to which they prioritize their adult lives to include caring for their ill sibling or making self-care their priority (Jewell, 1999).

There is accumulating evidence to suggest that family members report positive changes as a result of coping with the challenges of having a relative with mental illness, including
increased empathy, compassion, and understanding; better coping skills; greater closeness within their family of origin; and involvement in advocacy efforts to improve the mental health system (Marsh et al., 1996; Greenberg, Seltzer, & Judge, 2000; Aschbrenner, Greenberg, Allen, Seltzer, 2010). However, it is not clear how some well siblings find positive meaning in their experiences with their ill sibling while others do not. It may be that well siblings’ efforts to cope by trying to make meaning from their loved one’s mental illness may be related to the extent to which well siblings derive constructive significance from their experiences. This meaning-making process may, in turn, influence such factors such as willingness to engage in caregiving and the prioritization of self-care needs and sibling needs (Park et al., 2008).

Personal loss due to mental illness has also gained attention over the past ten years as a phenomenon of psychological interest (Murray, 2001; Harvey & Miller, 1998). Research has indicated that relatives of individuals with serious mental illness experience significant loss and subsequent grief reactions related to the onset of illness (Davis & Schultz, 1998; Miller et al., 1990; Solomon & Draine, 1996). Parents of adult children with mental illness have reported experiencing both a loss of their adult child’s potential to lead a normal life as well as a loss of freedom in their own lives (Ryan, 1993). Adults with mental illness have reported a loss of opportunities within society, a loss of prior relationships, and a loss of skills and abilities (Stein & Wemmerus, 2001). Despite the losses reported by adults coping with mental illness and their parents, little is known about how personal losses associated with having a brother and sister with mental illness affect well siblings’ behaviors, attitudes, and experiences. Well siblings, like other family members, may experience personal losses associated with their increased responsibilities as primary or secondary caregivers, and may also struggle to cope with their sibling’s loss of prior functioning and future goals (Lefley, 1989; Stein, et al., 2005). Despite the
stress associated with these losses, siblings may continue to manage their sense of loss, and simultaneously engage in caregiving, in efforts to prioritize self-care and sibling care, and in attempts to draw meaning and a sense of growth from these losses. Knowledge of their ill sibling’s former self and of their loss in prior functioning may also spur on efforts to become involved in caregiving and support activities after the onset of illness. Overall, better understanding of the role of loss and coping in well siblings may allow for the creation of effective services and programs that address their unique needs.

The present study examines the experiences of 103 adult well siblings of individuals with serious mental illness. The study examines the role of demographic factors, perceived severity of siblings’ illness, self-reported meaning-making coping efforts, and perceptions of personal loss in accounting for well siblings’ reports of caregiving, prioritization of sibling needs and stress-related growth. Well siblings perceptions of their siblings’ illness severity and dependence were conceptualized as basic factors that may contribute to reports of current and future intentions to provide care, stress-related personal growth, and self-care and sibling care priorities. Given that some well siblings have reported that involvement with their sibling with mental illness is gratifying and fulfilling (Greenberg, et al., 1997), the present study assessed well siblings’ reports of two types of meaning-based coping efforts (i.e., positive reappraisals and emotional processing) to understand their potential role in reports of caregiving, prioritization of sibling needs, and stress-related growth. The present study also examined the role of personal loss, after partialling out the effects of demographic and illness severity factors and meaning making coping processes, in describing well siblings’ patterns of caregiving, growth, and prioritization of self-care and sibling care. Taking into consideration a stress and coping framework, personal loss due to mental illness may spur on siblings’ efforts to make
adaptations, including finding or creating meaning, which may, in turn, influence experiences of caregiving, self-care and sibling care priorities, and reports of stress-related growth. A review of relevant literature regarding these constructs is presented to provide a framework for the present research.
CHAPTER I. LITERATURE REVIEW

Serious Mental Illness

According to the Diagnostic and Statistical Manual – Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association, 2000), “serious” mental illnesses are defined by markedly severe impairments in one or more major areas of functioning (i.e., employment, independent living, and self-care) over significant portions of time since the onset of illness. Similarly, the U.S. Department of Health and Human Services (2007) has conceptualized serious mental illness as a diagnosable mental disorder in persons age 18 or over that is long lasting and severe enough to seriously interfere with one’s ability to engage in major life activities. Most commonly, the term “serious mental illness” has been applied to disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, bipolar disorder and severe forms of other disorders, such as major depression (NAMHC, 1996).

Prior estimates have shown that, of the 10-11 million people diagnosed with mental illness in any given year (or 5-6% of the adult U.S. population), approximately 5-6 million people (or 3% of the adult U.S. population) meet criteria for serious mental illness (U.S. DHHS, 1999). Most studies of family caregivers of adults with serious mental illness have included eligibility criteria that require participants to report that the target family member has been diagnosed with a serious mental illness as defined by the DSM-IV (Jewell & Stein, 2002, 1997; Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997; Greenberg, Seltzer, Orsmond, Krauss, 1999).

Caregiving Among Well Siblings of Adults with Serious Mental Illness

Many well siblings do not provide extensive care for their brother or sister with serious mental illness because their parents serve as primary caregivers. However, as parents’ age and
their health and mortality risks increase, many become unable to provide care to their adult children with mental illness (Lefley & Hatfield, 1999). Given that few adults with serious mental illness are likely to have spousal or other intimate relationships that would warrant caregiving (Tsuang & Faraone, 1997), parents often turn to well siblings to take on caregiving responsibilities (Earl, 2005; Hatfield & Lefley, 2005; Jewell & Stein, 2002). Available siblings may also act as a reliable source of caregiving, support, and advocacy for their brother or sister with mental illness, particularly as services from mental health professionals fluctuate based on changes in symptom severity and functioning (Lukens & Thorning, 2011). Although the sibling relationship remains the longest and most enduring relationship throughout the lifespan (Cicirelli, 1995), the caregiving and support role of well siblings is not well understood. Sibling relationship patterns from childhood were described by Bedford (1989a, 1989b) as demonstrating the hourglass effect, where interactions and closeness gradually decrease as early adulthood approaches, remain relatively low during middle adulthood, and steadily increase during older adulthood as parental mortality becomes imminent (Lukens & Thorning, 2011).

Prior studies have failed to give precise estimates of the percentage of siblings in each age group currently acting as primary caregivers for their brother or sister with mental illness, however, research has better estimated future expectations for caregiving among siblings.

Future expectations for caregiving have been divided into to two main forms of support: instrumental and emotional. Instrumental care refers to practical assistance, such as transportation to appointments, housing and financial assistance, and symptom management (Jewell, 1999; Horowitz & Reinhard, 1995). Emotional support, in contrast, includes efforts to express affection, communicate in a sympathetic, sensitive, and understanding manner, and help ill siblings to share their personal challenges and increase their ability to care for themselves.
Social support, such as providing companionship and increasing the ill sibling’s participation in family activities, has also been included in measures of current and future caregiving among well siblings (Jewell, 1997).

Results from a study comparing future expectations for caregiving among siblings of individuals with mental illness or mental retardation showed that only one-third of siblings of adults with mental illness expected to assume primary caregiving responsibilities in the future, as compared to almost 60 percent of siblings of adults with mental retardation (Greenberg, et al., 1999). These conclusions were echoed in a similar study of 210 elderly caregivers, of which almost all were parents of adults with severe mental illness, regarding planning for the future care of their loved one (Hatfield & Lefley, 2000). Results showed that 63% of elder caregivers had turned to the adult children’s sibling for help in planning the future, but about one-third of these well siblings were deemed not helpful.

In a more recent study of siblings recruited through elderly parents attending a workshop on future care planning, most siblings indicated that they expected to be involved in caregiving (Hatfield & Lefley, 2005). However, siblings reported that they were more likely to provide social and emotional, rather than instrumental support. Furthermore, one-fourth of siblings had never discussed the issue of future care with parents, and two-thirds had never discussed this issue with other siblings in the family of origin. When this issue had been discussed with siblings, approximately one-fourth of siblings reported conflict over coordination of care (Hatfield & Lefley, 2005). Smith, Greenberg, & Seltzer (2007) also conducted a study of siblings (N=137) as part of a longitudinal study of families of adults with schizophrenia. Findings showed that push and pull factors predicted emotional and instrumental support. Instrumental support was predicted by younger age, married status, greater perceived reciprocity
in the sibling relationship, onset of mental health problems during the sibling’s childhood (rather than during adulthood), greater perceived severity of behavioral problems, and a greater sense of personal gains. Similarly, married status, greater familial responsibility, greater reciprocity and better quality of relationship, and greater personal gains were all predictive of emotional support by siblings. Lower expectations for providing instrumental support in the future were predicted by perceptions of greater geographic distance and greater controllability over symptoms, whereas geographic distance was the only pull factor which impeded future expectations for providing emotional support.

**Demographic Factors**

In prior research, demographic variables, such as gender, age, and support group affiliation, have been shown to predict caregiving among well siblings. Regarding gender, past research has shown that female siblings were not only more likely to provide care than male siblings (Greenberg, Kim, & Greenley, 1997), but also reported providing greater amounts of current caregiving and a greater anticipation of future caregiving responsibilities (Earl, 2005; Greenberg, Seltzer, et al., 1999; Jewell & Stein, 2002). However, the role of gender in caregiving remains unclear, as prior research has also found that gender did not significantly predict caregiving behavior (Horowitz, 1993; Smith, Greenberg, & Seltzer, 2007). Although the effects of age on caregiving have not been extensively studied, existing research suggests that, as siblings and parents age, well siblings are increasingly depended upon for support and caregiving (Hatfield & Lefley, 2005; Jewell, 1999). However, situational factors, such as career demands (Earl, 2005), financial and time constraints (Marsh, 1998), and family demands (Earl, 2005; Hatfield & Lefley, 2005) including difficulty balancing family demands with the needs of the family of origin (Marsh, 1998), may intensify as well siblings age and increase well sibling self-
focus or act as barriers to future caregiving expectations. In contrast, Smith and colleagues (2007) found that neither competing work and family demands nor health problems among well siblings were significantly related to expectations of providing instrumental support and caregiving in the future. Finally, support group affiliation, such as membership in the National Alliance for Mental Illness, has been shown to predict greater levels of current and future intentions to provide care to ill siblings (Jewell, 1997).

Sibling Illness Severity

Well sibling perceptions’ of the severity of their siblings’ mental illness may also critically influence intentions to provide care and to prioritize their needs over the needs of their ill siblings (Greenberg, Kim, & Greenley, 1997). Although prior research has not examined the role of illness severity on the prioritization of needs, it has shown that siblings who perceived their ill sibling as having greater control over their symptoms viewed themselves as less likely to provide future caregiving, while those who perceived that their brother or sister was currently experiencing severe symptoms expressed stronger expectations that they would provide care in the future (Smith, Greenberg, & Seltzer, 2007). Research has also suggested that well sibling perceptions that ill siblings were resistant to mental health treatment and noncompliant with medication impeded well sibling involvement in future caregiving (Hatfield & Lefley, 2005). As mentioned previously, the impact of “pull factors” on sibling caregiving have also been examined. Instrumental support among well siblings has been predicted by greater perceived severity of ill sibling behavioral problems, whereas lowered expectations for instrumental caregiving have been predicted by perceptions of greater symptom controllability (Smith, Greenberg, & Seltzer, 2007).
Mental Illness Compared to Physical Illness or Intellectual Disability

Given that family members of people with lifelong physical disability face similar caregiving dilemmas as those of individuals with serious mental illness, researchers have examined whether the nature of the illness affects patterns of sibling involvement in caregiving. When parents are no longer able to provide care to their adult children with physical disability, they often look to non-disabled siblings to help their brother or sister remain living in the community rather than accept placement in institutional care (Dew, Baladin, & Llewellyn, 2008). The role of non-disabled siblings in assisting in the smooth transition of care is not currently well understood (Hemming, Hutton, & Pharoah, 2006). Unfortunately, prior studies of adult sibling relationships in this context have focused on physical disabilities which have cognitive or psychological components, such as cerebral palsy, mental retardation, and developmental disabilities (Davis & Salkin, 2005; Burton & Parks, 1994; Begun, 1989), making it difficult to tease apart the ways in which sibling expectations for caregiving may differ on the basis of physical, intellectual, or mental illness.

In contrast to siblings with mental illness, however, existing research suggests that the experience of having a brother or sister with a physical or intellectual disability may improve the psychological strength of non-disabled siblings (Burton & Parks, 1994). In a study of 329 siblings of adults with mental retardation or mental illness, siblings of people with intellectual disability reported closer patterns of contact, more pervasive effects of their sibling on their life, and an overwhelming assessment of their sibling relationship as mostly positive (Seltzer, et al., 1997). These results contrasted with reports from well siblings of people with mental illness, which were predominantly negative. In a recently-published longitudinal study, siblings of adults with mild intellectual deficits or mental illness were compared to a group of sibling pairs in
which neither member had mild intellectual deficits or reported ever having been diagnosed with a mental illness (Taylor, Greenberg, Seltzer, & Floyd, 2008). When compared to sibling pairs without intellectual deficits or mental illness, siblings of adults with intellectual deficits reported greater contact, but less affective closeness. However, siblings of adults with mental illness reported more psychological distress and less psychological well-being when compared to non-affected sibling pairs. These differences may be due to the lifelong nature of many physical or intellectual disabilities, which provide siblings with ongoing opportunities to cope with the challenges of having a brother or sister with a disability (Dew, et al., 2008). In contrast, mental illness often develops in adolescence or young adulthood in the context of a mental health crisis, which requires adaptation to devastating changes in the behavior of their sibling and gives rise to feelings of loss regarding their former relationship with the mentally ill sibling. Furthermore, serious mental illness may include fluctuations between symptom-free periods and increases in problematic behavior, which may give well siblings the impression that symptoms are intentional or manipulative rather than attributable to mental illness (Seltzer et al., 1997).

Uncertainties regarding the trajectory of mental illness and the legitimacy of support needs may lead to feelings of resentment or preferences for self-focus among well siblings, making it more unlikely that well siblings will assume active caregiving roles or oblige to expectations for future caregiving. Although further research into the effects of physical and intellectual disability on adult siblings is needed, there are urgent needs for research into the factors that explain resiliency in well siblings of adults with serious mental illness. The current study aimed to address both the positive and negative features associated with having a brother or sister with serious mental illness in an effort to capture potential resiliency factors.
The prioritization of self-care and sibling care has not been extensively studied in prior research on adult siblings of individuals with serious mental illness. Based on findings from qualitative portions of a study of 111 adult well siblings (Jewell, 1997), Jewell (1999) developed the Self and Sibling Care Measure (SSCM), which captured well siblings’ endorsement of three approaches to the prioritization of self-care versus sibling care. The prioritization of self and sibling needs among well siblings has been conceptualized into three categories: “balance” toward personal and ill sibling needs, in which well siblings place equal emphasis on the support and caregiving needs of their brother or sister with serious mental illness, “ambivalence” toward self and sibling care needs, in which well siblings hold simultaneous, conflicting feelings toward their needs and their ill sibling’s needs, and “self-focus,” in which well siblings prioritize their own needs over the caregiving needs of their brother or sister with serious mental illness (Jewell, 1999). The SSCM was found to be relatively distinct from caregiver burden, current caregiving behavior, and felt obligation toward sibling care. When compared with siblings’ reports of caregiver burden, the study showed that the SSCM accounted for greater variance in reports of family satisfaction and guilt. Further research is needed to examine the factors that predict self-care and sibling care commitments, which may also have implications for current and future expectations for caregiving and personal growth among well siblings of adults with serious mental illness. The current study aimed to clarify the role of demographic characteristics, illness severity and dependence, meaning making coping processes, and personal loss in predicting the degree to which well siblings prioritize self-care compared to sibling care. Because self-care and sibling care priorities appear to be more categorical than dimensional in nature, Jewell’s (1999)
subscales of ambivalence, balance, and self-focus were used as criterion variables to test the predictive value of the aforementioned factors.

**Stress-Related Growth**

In addition to engaging in caregiving and contemplating their involvement in the life of their relative with mental illness, well sibling and parents have reported stress-related growth and other personal gains as a result of having a family member with mental illness (Dixon, 1997; Jewell, 1999; Lukens, Thorning, & Lohrer, 2004; Aschbrenner, et al., 2010). Stress-related personal growth measures the extent to which people thrive or experience varying levels of personal growth following traumatic or stressful life experiences (Park, Cohen, & Murch, 1996). Schaefer and Moos’ (1992) review of the literature on life crises and personal growth identified three major types of stress-related positive outcomes, including enhanced personal resources (e.g., better self-esteem), enhanced social resources (e.g., better relationships with friends), and the formation of new or enhanced coping skills (e.g., better problem-solving skills). These outcomes were used to form the measure of stress-related personal growth used predominately in the stress and coping literature (Park, Cohen, & Murch, 1996).

Prior studies of serious mental illness have tended to emphasize the negative effects of the illness on the family, yet several studies highlight the positive changes that may result from coping with the experience of having a family member with serious mental illness. In a study conducted by Greenberg, Seltzer, and Judge (2000), 171 mothers of adults with mental illness reported that other family members, including well siblings, had developed a greater appreciation of their inner strengths, an enhanced social network, increased sensitivity, and stronger family ties as a result of having a relative with mental illness. Similarly, well siblings have credited the experience of having a sibling with mental illness with the development of their own sense of
independence, self-reliance, resiliency, and assertiveness (Kinsella & Anderson, 1996). In the aforementioned survey conducted by Marsh and colleagues (1996), siblings reported gaining a positive sense of meaning from the experience, including enhanced personal competence, a greater appreciation for their sibling’s life and mental health, and a healthier perspective on their priorities. Additionally, in a study examining expectations about future caregiving roles among well siblings of adults with schizophrenia, those who felt a greater sense of personal growth through coping with their sibling’s illness were more likely to endorse future expectations to provide instrumental support to their ill sibling than those who experienced fewer gains (Smith, et al., 2007).

Prior research suggests that positive reinterpretations of stressful life experiences may act as a determinants of stress-related growth (Taylor, 1983). Additionally, research supports the notion that factors tapping the stressfulness of the negative event, for example, the severity of a loved one’s mental illness or the extent of personal loss, may be predictive of stress-related growth (Schaefer & Moos, 1992). The current research aims to test the role of both resources and potential stress factors, such as meaning-making coping and personal loss, in predicting stress-related growth.

The Stress and Coping Framework: The Role of Meaning Making Coping Processes and Personal Loss in Predicting Involvement and Growth

Given that development literature has captured many of the detrimental aspects of serious mental illness in the family, there is a need to broaden our assessment of the family experience of mental illness to consider a full range of potential responses, including positive transformations, ambivalence, and loss (Dykens, 2005; Smith, et al., 2007). Family researchers have focused on the burden associated with having a close family member with mental illness without fully
conceptualizing the losses associated with mental illness or examining family members’
simultaneous efforts to search for meaning in response to serious mental illness (Stoneman,
1998; Jones, 1997). Exclusive attention to burden limits the ability to detect other possibilities
and narrows the development of conceptual and practical tools to address the challenges of
mental illness and increase family strengths.

By taking into account reports of losses as well as positive changes associated with
having a sibling with mental illness (Marsh & Dickens, 1997; Seligman, Steen, Park, & Peterson,
2005), the stress and coping model may provide ways to better understand a broader range of
family member experiences (Dykens, 2005). The stress and coping model allows for the
possibility that families are managing the stress of mental illness and coping with the ongoing
experience of having a relative with mental illness (Hodapp, 2002). It also implies that family
members may experience multiple losses in response to mental illness, but that these losses may
not impede efforts to provide caregiving, to balance family member needs, or to attain a sense of
growth or meaning from a loved one’s mental illness. In fact, efforts to adapt to and cope with
the losses associated with a family members’ mental illness may even increase involvement in
caregiving and enhance growth experiences. An examination of the role of personal loss and
meaning making coping processes complements efforts to explore a wider range of responses to
mental illness, including stresses and resources underlying well siblings’ experiences.

*Meaning Making Coping Processes*

The search for meaning in coping with stressful and traumatic life experiences has been
widely acknowledged in previous studies of loss and meaning-making (Davis, Wortman,
Lehman, & Silver, 2000; Gillies & Neimeyer, 2006; Janoff-Bulman, 2004). However, few
studies have attempted to examine potential resiliency factors in cases of serious mental illness,
such as the search for positive meaning among family members coping with the mental illness of a relative. The search for meaning has been shown to be both adaptive (e.g., Davis, Nolen-Hoeksema, & Larson, 1998) and potentially associated with distress (e.g., Bonanno, Papa, Lalande, Zhang, & Noll, 2005).

Meaning has been defined as the process of making sense of or deriving insight and understanding from significant loss or other highly stressful events (Park, 2008). Meaning making refers to previous deliberate attempts to reduce discrepancies between global and situational meaning in response to a stressful event and to restore global meaning when it has been disrupted or violated. Global meaning represents an individual’s set of global beliefs and goals from which they derive a sense of purpose and direction in life. When confronted with a stressful event (e.g., a sibling’s mental illness), individuals appraise the event, which represents situational meaning. Situational meanings can shatter the sense of global meaning, leading to attributions which increase the discrepancy between global and situational meanings. Stressful life experiences and feelings of loss initiate “meaning making” coping efforts to restore alignment between global and situational meanings (Park, 2008). By reducing the discrepancy between global and situational meanings, meaning making coping has been hypothesized to lead to better adjustment (Collie & Long, 2005; Gillies & Niemeyer, 2006). Meaning making coping processes may involve deliberate attempts to change situational or global meaning systems, understand the situation in a different way, and reform one’s beliefs and goals in order to regain consistency among them (Park, 2008).

Meaning making coping processes, within the stress and coping literature, have been frequently assessed using two processes: positive reappraisals and emotional processing (Gillies & Neimeyer, 2006; Park, et al., 2008). Positive reappraisals include attempts to see the stressful
life event in a more positive light (Carver et al., 1989). Lazarus and Folkman (1984) regarded this tendency as a type of coping aimed at managing distressing emotions (Carver et al. 1989), however, the reinterpretation of stressful events in positive terms may also alter situational and global meaning systems. Prior research has shown that positive reappraisals predict factors such as posttraumatic growth and life meaningfulness, which predict better adjustment outcomes, such as psychological well-being and improved quality of life (Park et al., 2008; Dirksen, 1995; Roesch et al., 2005). Emotional processing involves actively attempting to explore meanings and come to an understanding of one's emotions (Stanton, Kirk, Cameron, Danoff-Burg, 2000). In coming to understand and make meaning of emotions, one may come to a more satisfying attribution regarding the stressor, reduce its perceived threat, or find benefit in one's experience, which in turn may promote positive adjustment and personal gains. Considering that many emotion-focused coping scales have been contaminated with distress or self-deprecatory content (e.g., "I get angry and really blow up") (Stanton, Danoff-Burg, Cameron, Ellis, 1994), the development of the emotional processing scale was an effort to create a more neutral coping scale that did not inflate relations obtained between emotion-oriented coping and maladjustment (Stanton, Kirk, Cameron, Danoff-Burg, 2000).

Past research on siblings of adults with serious mental illness has examined various coping processes such as competent coping (Han, 1995), emotion- and problem-focused coping (Morris, 2002; Halvorson, 1997), adaptive coping (Solomon & Draine, 1995), and specific coping resources and strategies (Friedrich, Lively, & Rubenstein, 2008; Blasko, 2007). According to Friedrich, Lively, and Rubenstein (2008), coping strategies represent the concrete strategies well siblings use to deal with the problems they encounter in response to the challenges of mental illness. Prior research has focused on adaptive coping efforts such as the use of
instrumental and emotional social support, religious or spiritual coping, and efforts to acquire greater knowledge of mental illness (Gerace, Camilleri, & Ayres, 1993; Stalberg, Ekerwald, & Hultman, 2004; Kinsella & Anderson, 1996). In an exploratory study testing the meaning-making model of coping with loss or a significant life stress, Park (2008) found that emotional processing was related to reductions in discrepancies of the world as fair and reductions in goal violations. Higher perceived discrepancies between appraised and global meaning were also related to effortful meaning making, including emotional processing, but less consistently so, suggesting that meaning making coping efforts may be variably efficient in reducing discrepancies. In another exploratory study of meaning-making in cancer patients, Park and colleagues (2008) used positive re interpretations to assess meaning-making coping and found it was related to survivors’ growth and meaningfulness. Using a longitudinal design with the same sample, positive re interpretations at Time 1 were related to growth at Time 2, and to the restoration of just-world beliefs at Time 2. Furthermore, positive reappraisals at Time 1 predicted 33% of the variance in growth and 28% of the variance in life meaningfulness at Time 2. The structure of the process was remarkably stable over the two time points, lending support for the role of meaning making coping processes in helping to reduce discrepancies between global and situational meanings that occur in response to significant life stressors. Positive reappraisal and emotional processing were identified as most relevant to the current study given that they represent coping processes which support meaning making in the midst of highly stressful circumstances (Park, 2008; Folkman, 1997), such as the experience of having a brother or sister with serious mental illness.

Well siblings have acknowledged a need for preparation to replace parents in fulfilling the social, emotional, and instrumental support needs of their brothers and sisters with mental
illness (Hatfield & Lefley, 2005), and have reported that they often lack the knowledge and resources to take over parental roles (Friedrich, Lively, & Rubenstein, 2008). Given these challenges, adjustment to caregiving and decision making regarding the prioritization of self-care and sibling needs may be particularly difficult for well siblings (Greenberg, Seltzer, Orsmond, et al., 1999; Jewell, 1999). The unique dynamics involved in sibling relationships, which often combined empathic and antagonistic behavior, may also impact the trajectory of meaning-making coping and loss experiences (Hetherington & Clingempeel, 1992). These findings underscore the importance of understanding the potential role of meaning making coping processes in the development of well siblings’ personal strengths and in the reinforcement of sibling involvement. Although deliberate meaning making efforts through coping with stressful life experiences have been frequently assessed using the constructs of positive reinterpretation and emotional processing (Park, 2008; Stanton, Danoff-Burg, & Muggins, 2002), no study to date has employed these constructs to assess meaning making efforts in well siblings. The current study assessed these processes to determine whether they predict patterns of caregiving behaviors and intentions, the prioritization of self care versus sibling needs, and stress-related growth.

Personal Loss

The onset of mental illness is a traumatic event for the family which often changes the trajectory of expectations and involvement among parents and siblings (Lukens & Thoring, 2011). Mental illness often strikes families when siblings approach early adulthood, a time when typical family interaction patterns involve helping to launch children into the tasks and responsibilities of emerging adulthood and independent living (Thorning, 2004). However, when serious mental illness strikes, the normative life course, particularly for the affected
sibling, remains elusive or may be discarded altogether. Individuals with mental illness face interruptions or delays in normal developmental milestones associated with emerging adulthood, including attending college, obtaining employment, getting married, and raising children (Seltzer, Greenberg Krauss, & Hong, 1997). At the same time, well siblings may choose to withdrawal or take on little to no responsibility for providing care and support to their sibling with serious mental illness. Well siblings who remain actively involved are faced with the complex and fluctuating needs of their brother or sister with mental illness, and at the same time receive little to no preparation or information regarding the illness, and limited access to professional support or interaction (Lukens & Thorning, 2011; Lukens, Thorning, & Lohrer, 2004).

Well siblings of adults with serious mental illness are likely to report personal loss considering that many have reported feeling invisible, abandoned, or forgotten by their families during the transition from adolescence to adulthood (Lukens, et al., 2004; Marsh & Dickens, 1997; Marsh, 1998). Some well siblings have also indicated that their parents were not able to meet their needs because they were preoccupied with the needs of their child with mental illness (Lukens et al., 2004; Marsh, 1998, Marsh & Dickens, 1997; Thorning & Lukens, 1999). In past research and in narrative accounts of well siblings, role and boundary confusion has been reported, with many well siblings taking on therapeutic and parental roles within their family of origin (Lukens et al., 2004; Marsh, 1998; Marsh & Dickens, 1997). Well sibling responses have varied from striving to be perfect in order to reduce family burden to acting out in order to gain attention (Lukens et al., 2004; Marsh, 1998; Marsh & Dickens, 1997). Well siblings have also reported grief over the loss of a normal childhood and family life (Lukens, et al., 2004), and have
been found to grieve the loss of their sibling’s potential to lead a “normal life” (Brown, 1999; Marsh, 1997; Ryan, 1993; Stein & Wemmerus, 2001).

Although prior studies have supported the important role of meaning-based coping experiences among family members, these potential resiliency factors never occur in isolation, and are clearly accompanied by feelings of loss and demoralization (Marsh & Dickens, 1997). Individuals with mental illness, their parents, siblings, and other family members contend with changes in severity of the illness throughout a lifetime, and caregiving and support responsibilities may often interfere with individual achievement for both well and ill siblings as well as parents (Lukens & Thorning, 2011). Considering that the onset of serious mental illness delays or interrupts normative life stages among family members, prior research has indicated that personal loss may be a central experience of family members of individuals with serious mental illness. For example, well siblings’ have frequently reported negative outcomes including hopelessness and helplessness, and a sense of guilt, and lowered self-esteem (Marsh et al., 1996; Marsh & Dickens, 1997). Examining personal loss due to mental illness in tandem with meaning making coping processes complements efforts to capture a balance of positive and negative aspects of the well sibling experience.

Personal loss due to mental illness includes the “subjective experience of loss due to psychiatric disability and psychosocial losses due to changes in functioning and a lack of access to valued social roles” (Stein, 2005; Stein, Dworsky, Phillips, & Hunt, 2005). Personal loss has been studied within families who have a loved one with a serious mental illness (Stein & Wemmerus, 2001) and among individuals diagnosed with serious mental illness (Stein, et al., 2005). In prior conceptualizations of loss, subjective (i.e., the experienced of personal loss within the individual) and objective (i.e., personal loss as recognized by others) forms of loss
have been identified and used to determine the magnitude of loss. Primary and secondary losses have also been described, where primary loss refers to the loss event and secondary loss arises from the primary loss. For instance, primary loss might refer to the loss of capacity as a result of an illness (Kelley, 1998), which results in secondary losses in the planned future, in prior relationships, and in financial security. Secondary losses may arise or become evident over time and alter the grieving process involved in the primary loss (Murray, 2001). Research has emphasized that personal loss may force the individual to make adaptations, including finding or creating meaning, as a way of coping with the loss experience (Harvey, 2001; Emmons, Colby, Kaiser, 1998). Research indicates that reactions to personal loss are affected by positive individual characteristics (e.g., Krupp, 1987), social support (Raphael, 1984), and overall coping abilities (Parkes, 1986) and that, regardless of the type of loss, there are commonalities across diverse loss experiences (Harvey & Miller, 1998).

The study of personal loss due to serious mental has focused on grief reactions experienced by family members rather than the impact of loss on caregiving (Davis & Shultz, 1998; Miller, Dworkin, Ward, & Barone, 1990; Solomon & Draine, 1996). Research has indicated that relatives of individuals with serious mental illness experience significant loss and subsequent grief reactions related to the onset of illness (Davis & Schultz, 1998; Miller et al., 1990; Solomon & Draine, 1996). Family members’ response to personal loss from mental illness may be similar to grief reactions to death given that the ill relative is not the same as before the onset of illness and that relatives may grieve the loss of aspirations that they once held for their ill relative’s future (Stein et al., 2005; Solomon & Draine, 1996; Parker, 2003). For many family members, efforts to move on from the loss may feel like a betrayal of the person that they feel has been lost (Jones, 2004). Nevertheless, families may be trying to construct new meanings and
help their ill loved one live a meaningful life. In this case, viewing the onset of serious mental illness as similar to the death of a loved one may be harmful (Stein & Wemmerus, 2001). Although research has focused on these grief reactions, grief associated with coming to terms with a loved one with mental illness has been conceptualized as distinct from other forms of grief in several ways. A diagnosis of mental illness may result in multiple future losses for the ill family member and their relatives, yet the significance of these losses often go unrecognized by society (MacGregor, 1994). The experience of grief is often coupled with new expectations for ongoing caregiving and support, and has been associated with greater objective and subjective burden in family members (Solomon & Draine, 1996). Furthermore, loss may be compounded by feelings of anger and experiences of stigma related to mental illness (Jones, 2004). In light of these distinctions, the focus of the present study is on the perceptions and experiences of loss rather than grief reactions.

Qualitative studies have demonstrated the unique aspects of personal loss due to mental illness as experienced by family members. In a study of five mothers of adults with schizophrenia using an ethnographic approach (Ryan, 1993), results showed that mothers experienced both a loss of their adult child’s potential to lead a normal life as well as a loss of freedom in their own life. In another qualitative study, 22 family members, including adults with schizophrenia, parents, and well siblings, were interviewed about the impact of schizophrenia on family life (Stein & Wemmerus, 2001). Family members reported distress related to personal and social changes associated with the family member’s diagnosis of schizophrenia. Adults with schizophrenia reported experiencing a loss of skills and abilities, of prior personal relationships, and of opportunities within society. Parents also reported loss, especially as it relates to the loss of their child’s abilities and potential (Stein and Wemmerus, 2001).
These qualitative studies led to the development of a measure of personal loss due to mental illness (Stein et al., 2005). The psychometric properties of the Personal Loss from Mental Illness scale were originally tested on a sample of 158 adults with mental illness and identified four types of loss: loss of roles and routine, loss of former relationships, loss of former self, and loss of future. For young adults with psychiatric disability, personal loss due to mental illness was associated with greater loneliness, more severe psychological symptoms, more problematic drinking, and less positive well-being. Another study examined personal loss due to mental illness in association with aspirations, ability, and support to attend college (Stein, 2005). Using a sample of 80 adults with psychiatric disability, results showed that multiple elements of personal loss were associated with fewer aspirations and plans to attend college and with self-perceptions of less intellectual and emotional capacity for college. Results also indicated that overall illness severity was not associated with self-assessments of capacity to attend college, which suggests that personal loss due to mental illness played a distinct role in adult’s views of their ability to pursue goals for higher education and lead a normal life. The experience of personal loss due to mental illness as experienced by family members has not been extensively studied quantitatively, and no study to date has quantitatively examined personal losses due to mental illness as experienced by well siblings. The present research aims to clarify the role of personal loss in the experiences of well siblings of adults with serious mental illness.

Given that nearly all siblings have reported strain and psychological and tangible losses associated with having a siblings with serious mental illness (Lohrer, Lukens, & Thorning, 2006), personal loss is believed to have the most salient impact on reports of caregiving, growth, and the prioritization of needs, after taking into account demographic and illness severity factors and meaning-making coping efforts. Although efforts to make meaning out of a siblings’ mental
illness may help well siblings to readjust their expectations and restore hope for the future, within the current study personal loss was thought to have a greater impact on caregiving, self-care and sibling care priorities, and stress-related growth due to its multifaceted nature and wide-ranging effects. The experience of personal loss due to a sibling’s mental illness may affect well siblings’ current and future expectations for the sibling relationship and perceptions of the importance of the prior functioning of the ill sibling. Personal loss may also change well siblings’ perceptions of their own identity before and after the onset of mental illness in the family. The personal loss construct captures well siblings’ responses to unwanted or unexpected changes in their future roles, routines, and aspirations. Considering the unpredictable nature and varying course of serious mental illnesses, aspects of personal loss are likely to be re-experienced by well and ill siblings throughout the lifespan. The repeated experience of personal loss may influence well siblings’ perceptions of the necessity of their caregiving and support role, and also enable siblings to process losses and derive a sense of growth from the loss experience. Compared to meaning making, personal loss appears more directly tied to the challenges and distressing experiences associated with mental illness in the family. Furthermore, while all siblings have seemingly reported losses in response to the onset of illness, not all report positive experiences or the ability to make meaning from their loss.

Although personal loss may reduce well siblings’ willingness to provide care and balance self and sibling care needs, literature on personal has also provided theoretical models of reactions to loss and steps toward recovery (Harvey, Orbuch, & Weber, 1990; Neeld, 1990). When applied to well siblings, these models suggest that, given the help of supportive others and with the experience of transformational events, siblings may derive meaning from the personal losses associated with having a brother or sister with mental illness (Stein, et al., 2005).
Effectively coping with a sense of personal loss may be an important psychological factor related to a confidence and readiness to face the challenges of sibling caregiving responsibilities. Personal loss may differentially affect caregiving behaviors, growth, and the prioritization of needs depending on whether well siblings have been able to successfully derive a sense of meaning and growth from the loss. Alternatively, well siblings may simultaneously engage in efforts to cope with personal loss and still maintain a willingness to provide caregiving, to prioritize sibling needs, and to search for growth despite the stress associated with serious mental illness.

The Present Study

The present study examined the experiences of 103 well siblings who have a brother or sister with a serious mental illness. The research assessed the role of well siblings’ perceptions of personal loss and meaning-related coping in describing well siblings reports of caregiving for their sibling with mental illness, their prioritization of personal vs. sibling needs, and stress-related personal growth. Based on previous research, well siblings’ demographic characteristics and perceptions of the illness severity of their siblings were expected to predict criterion variables. Specifically, siblings who were older and female and who reported greater support group affiliation and higher ratings on sibling illness severity were hypothesized to also report higher scores on measures of stress-related growth, current caregiving and intentions for caregiving, and greater ambivalence with regard to prioritization of personal needs over sibling needs.

The present study examined the relative contribution of personal loss scores in accounting for variation in scores on measures of caregiving, growth, and the prioritization of needs beyond that of well sibling demographic characteristics, perceptions of illness severity of
siblings with mental illness and meaning-related coping processes. Scores on measures of
meaning making coping (i.e., positive reappraisals, emotional processing) were expected to
statistically predict a larger portion of the variance in growth, caregiving, and the prioritization of
needs than demographic and severity factors. However, personal loss was hypothesized to
predict the largest variance in these criterion measures, above and beyond the contributions of
meaning-related coping processes.
CHAPTER II. METHOD

Recruitment

Participants in the present study consisted of a sample of 103 adults from across the United States who have a sibling with a serious mental illness. To be eligible to participate in the research, individuals needed to be at least 18 years of age and report having one sibling diagnosed with a serious mental disorder (American Psychiatric Association, 2000). Participants were encouraged to participate in the research regardless of their current level of contact with their ill sibling. The Human Subjects Review Board (HSRB) of Bowling Green State University reviewed and approved data collection methods used in the present research.

Participants were recruited through study announcements placed on websites related to mental illness (e.g., schizophrenia.com) and in newsletters distributed primarily by the National Alliance on Mental Illness (NAMI). Participants were also recruited through telephone and email contacts with well sibling support group facilitators and leaders of state and local chapters of NAMI (see Appendix A). Announcements targeted siblings themselves and parents who could refer their adult offspring to the study (see Appendix B). A link to the online survey was provided to participants in study announcements and through telephone contacts. All questionnaires were completed anonymously by well siblings. Participants gave their informed consent to participate in the study through an informed consent webpage that required (through a response button) acknowledgement that they were presented with the risks and benefits of participating in the project and that they met eligibility requirements for the study (see Appendix C).

To distribute study announcements, a total of 287 calls were made and 167 emails were distributed to sibling support group facilitators, leaders of state and local chapters of the NAMI,
and individual siblings who expressed interest in the study. A total of 103 questionnaires were valid for inclusion in the current study, with 3 participants’ responses considered to be invalid because their ill sibling was no longer living.

Sample Characteristics

A total of 103 eligible participants (81 women and 22 men) were recruited for the present study, with 21 (20%) affiliated with NAMI, 7 (7%) affiliated with a family support group, 11 (11%) affiliated with both NAMI and a family support group, and 64 (62%) reporting no affiliation with either NAMI or a support group. The large number of responses from siblings not affiliated with either NAMI or a support group may be due to recruitment efforts that targeted visitors of websites and message boards related to mental illness, which may also act as a form of support for siblings. It is also plausible that these participants were recruited from NAMI or support group affiliated parents who shared the announcement information with their well adult children. Descriptive statistics of well sibling demographic characteristics can be found in Table 1.

The average age of respondents for the entire sample was 38.9 years (SD = 13.8). A majority of the respondents were European American (90.3%). Approximately one-half (52%) of participants in the present sample were married or living with a partner, and reported having an average of one to two children (M = 1.20, SD = 1.56). A majority of the overall sample is highly educated (94%), reporting that they had either completed “some college” (30%), “a 4 year college degree” (32%) or an “advanced degree (graduate training)” (32%). Over two-thirds (70%) of the sample worked either part- or full-time, with 40% earning less than $30,000 annually, 24% earning between $30,000-59,999, and 27% earning over $60,000. A majority of the sample identified themselves as being Christian or Catholic.
(59%), or as having no religious affiliation (26%). When asked about mental health, 43% of respondents indicated they had been diagnosed with a mental health problem. Of participants who reported a prior mental health diagnosis, over half (53%) were diagnosed with depression or dysthymia.

**Respondent’s Ill Sibling Demographics**

When asked to provide information about their sibling with serious mental illness, respondents reported that their ill sibling tended to be male (64%), single (76%) with no children (77%), and in their late 30s (M =38.4, SD = 13) (see Table 2). Many participants (70%) indicated that their ill siblings’ education level included at least “some college,” and 26% of ill siblings were reported to have a “4 year college degree” or an “advanced degree (graduate training).” Two-thirds (64%) of participants reported that their ill sibling had been diagnosed with schizophrenia or schizoaffective disorder, with the majority (68%) of the overall sample having been diagnosed between 5-10 years (26%), 10-20 years (19%), or more than 20 years (23%). When asked about their ill siblings’ employment status, 76% of participants indicated their ill sibling was “unemployed” or “disabled” and 46% indicated that their sibling did not make “enough money to make ends meet.” A majority (84%) of participants’ ill siblings were either living with a family member (37%), living independently with no formal supervision (34%), or were living in a group home (13%). Many participants (67%) also indicated that their ill sibling had a primary therapist, case manager, or social worker that they see on a regular basis. Descriptive statistics of ill sibling demographic characteristics can be found in Table 2.

**Involvement and Contact**
Participants were also asked about their involvement in the life of their ill sibling. Approximately one-fifth (18%) of the current sample reported that they act as a primary caregiver, or as the family member who feels most responsible for making sure their sibling is managing their illness. Of the 84 respondents who indicated that they were not the primary caregiver for their ill sibling, 60% reported that a parent currently held this role. Although the majority of the sample did not identify as primary caregivers, over half (52%) reported being “moderately involved” to “very involved” in the life of their brother or sister with mental illness. Similarly, 40% of all participants reported that they had either “a moderate amount of responsibility” or “a great deal of responsibility” in providing care to their ill sibling. Two-thirds (62%) of the overall sample reported being “moderately close” to “very close” to their ill sibling. Over half (53%) of respondent indicated that they were “not at all active” in family support or mental illness advocacy groups (e.g., NAMI), while 22% reported that they were either “moderately active” or “very active” in these groups.

Respondents indicated more frequent phone contact with their siblings (49% reported weekly to daily contact with their sibling over the phone) than face-to-face contact (29% indicated weekly to daily face-to-face contact, while 45% indicated having face-to-face contact less than once per month to “not all in the past year”). Almost half (45%) of the total sample reported living “within a 1 hour drive (about 0-50 miles)” from their ill sibling, while 32% reported living “within 1 day’s drive (301-1000 miles)” or that their ill sibling was “not easily reached by car.” Almost all (88%) of respondents indicated that they would like “more contact” or “the same amount of contact” with their ill sibling, with only 12% reporting that they would like to have “less contact.”
When asked about constraints to involvement in the life of their ill sibling, 37% of the overall sample indicated “poor” time availability and 45% indicated “poor” ability to be involved as a result of financial constraints. Two-thirds (69%) of participants also acknowledged that they felt “a lot” to “all” of their energy should be spent focusing on their own life and needs.

Measures

Demographic Variables and Illness Severity. Participants were asked to answer several questions regarding their own demographic characteristics as well as those of their ill sibling. Well siblings were asked for their gender, age, marital status, number of children, racial group, highest level of education, work status, annual income, state of residence, NAMI membership status, level of involvement in family member, sibling, and advocacy groups, religious preference, level of religiosity, and mental health diagnosis, if applicable. Well siblings were also asked about their ill sibling’s gender, age, marital status, number of children, level of education, employment status, current financial and living situation, geographical distance, primary psychiatric diagnosis, length of diagnosis, mental health services, severity of illness, and level of dependence. Two questions of the aforementioned demographic questions were used to assess well siblings perceptions of the severity of their siblings’ mental illness. Well siblings ratings of the severity of their siblings’ mental illness as well as their siblings’ level of dependence were used to assess illness severity level.

Sibling Contact and Involvement. Participants responded to questions about the extent of involvement and contact they currently have with their ill sibling. Well siblings reported whether they identified themselves as the primary caregiver for their ill sibling, and responded to questions about their telephone and face-to-face contact with their sibling. Well siblings also
rated their preference for contact with their ill sibling (i.e., more, less, about the same) as well as their level of involvement with and responsibility for their ill sibling. Finally, well siblings responded to questions about any time, financial, or personal constraints that may impede contact with their brother or sister with mental illness.

**Support Group Affiliation.** Participants were asked to rate their involvement in support and advocacy groups, such as NAMI and family support groups. Support group affiliation was scored based on whether participants’ reported being affiliated with no support groups, either a family/sibling support group or a NAMI support group, or both NAMI and a family/sibling support group. As a categorical variable with three groups, support group affiliation was dummy-coded across two variables for the purposes of regression analyses. The group with the largest sample size, no affiliation (N=64), serving as the reference group. Response options were dummy-coded into two categories, one of which compares no affiliation to affiliation in either NAMI or another support group and the other which compares no affiliation to affiliation in both NAMI and another support group.

**Meaning Making Coping Processes.** Two dimensions of coping often used in meaning research were thought to be most relevant to well siblings: positive reinterpretations and emotional processing (e.g. Boehmer, Luszczynska, & Schwarzer, 2007; Folkman, 1997; Park, 2005; Park, 2008, see Appendix H). The full COPE inventory asks participants to rate the extent to which they use each of 60 coping activities on a scale ranging from 1 (never) to 4 (very often) (Carver, Scheier, & Weintraub, 1989). The positive reinterpretation and growth (PRGS) subscale of the COPE consists of four items regarding attempts to see the illness in a more positive light (“I look for something good in what is happening”; α=.80). Although not part of the standard COPE, the emotional processing scale (EPS) supplemented the positive reinterpretation and
growth subscale and will be rated on the same response scale (Stanton, Danoff-Burg, Muggins, 2002). It consists of four items regarding attempts to understand one’s emotional reactions to the experience of having a sibling with serious mental illness (e.g., “I delve into my feelings to get a thorough understanding of them”; α=.82). These subscales have been shown to have satisfactory internal consistency (.80 for PRGS and .82 for EPS). Internal consistency for the present study was .83 for the PRGS and .90 for the EPS.

Meaning (Single Item). Single items used frequently used in meaning research were employed to assess overall meaning-making (i.e., “How much have you been trying to make sense of or find any meaning in the experience of having a brother/sister with a mental illness?”) and just-world beliefs (i.e., “When you think about having a brother or sister who has a serious mental illness, how much does it make you think that the world is NOT fair or just?”). An additional item assessed well siblings ability to make meaning of their experience (i.e., “How successful have you been in actually making sense of or finding meaning in the experience of having a brother/sister with mental illness?”). Respondents rated meaning items on a scale of 1 (not at all) to 4 (very often) (McIntosh et al., 1993; Michael & Snyder, 2005; Park, 2008, see Appendix K).

Personal Gains (Single Item). Based on the Personal Gains Scale (PGS) developed by Pearlin, Mullan, Semple, and Skaff (1990), participants reported on the sense of gain and growth they derive from coping with the challenges of mental illness through one open-ended question: “Briefly describe any kinds of personal gains that you feel as a result of having a sibling with a mental illness?” (see Appendix L).

Personal Loss. The Personal Loss from Mental Illness scale (PLMI; Stein, Dworsky, Phillips, & Hunt, 2005, see Appendix I) was adapted for use with well siblings. The PLMI was
developed to reflect the personal, relationship, and psychosocial losses reflected in having confronted the challenges of mental illness. Factor analysis has revealed four distinct factors in the PLMI: Roles and Routines, Former Relationships, Former Self, and Future. Internal consistency coefficients for the four subscales have ranged from .68 to .98, and the PLMI has shown convergent validity with measures of loneliness, psychiatric symptoms, and alcoholism and divergent validity with personal growth and positive well-being (Stein et al., 2005). The Personal Loss from Mental Illness-Sibling Version (PLMI-S) consisted of 20-items adapted for siblings, such as “Since my sibling illness, the plans I make for each day often do not get done”, which respondents rated on 5-point Likert scale (from 1= “Strongly disagree” to 5= “Strongly agree”). The internal consistency for the entire PLMI-S for the present study was .86.

Current Caregiving. The level of assistance provided by well siblings was measured by Current Caregiving Scale (CCS), which was adapted by Jewell (1997) from eight items developed by Horowitz (1993) and Horowitz, Tessler, Fisher, & Gamache (1992) to assess current emotional support, assistance with basic needs, and symptom management provided by well siblings of individuals with mental illness (see Appendix F). The CCS consists of 10 items (e.g. “In the past year, I have assisted my ill sibling with rides or assistance with transportation”) anchored on a four-point Likert scale (from 1= “None” to 4 = “Frequently”), and has demonstrated good internal consistency (α=.87) in prior research on well siblings (Jewell, 1997; Jewell, 1999). Cronbach’s alpha for the Current Caregiving Scale in the present study was .90.

Intentions to Provide Caregiving. The Intention to Care Scale (ICS) was developed by Jewell (1997) and was used to assess well siblings expectations that they will provide caregiving and assistance to their brother or sister with serious mental illness in the future (see Appendix G). The scale consists of 5 global items designed to assess intentions to provide caregiving in
areas of emotional support, basic needs, financial assistance, symptom management, and arranging for supportive services. Respondents were asked to indicate their agreement with each item, such as “I intend(expect to help my sibling with emotional support sometime in the future”, using a five-point Likert-type scale (from 1= “Strongly Agree” to 5=”Strongly Disagree”). Jewell (1997) found the internal consistency of the ICS was .82. The internal consistency for the ICS in the current study was high (α=.89).

**Stress-Related Personal Growth.** Park, Cohen, and Murch’s (1996) 50-item Stress-Related Growth Scale (SRGS) was developed into short form comprised of the 15 highest-loading items (Cohen, Hettler, & Pane, 1998, see Appendix J). A comparison of findings from prior studies has show good agreement for the 15 SRGS items that are most highly related to the total score (Hettler & Cohen, 1996; Park et al., 1996). The SRGS short form was used to assess ways that siblings believe they have experienced personal growth and other positive changes due to having a sibling with a mental illness. This measure includes items such as “I learned to find more meaning in life” and “I learned to reach out and help others.” Participants responded on a 3-point Likert scale ranging from 0= “Not at all” to 2= “A great deal.” The SRGS has demonstrated good internal reliability (α=.94) and test-retest reliability (.81) (Park, et al., 1996). In the current study, Cronbach’s alpha for the SRGS was high (.94).

**Self and Sibling Care Measure.** The Self-and-Sibling-Care Measure (SSCM) developed by Jewell (1999) measured the extent to which well siblings prioritize their personal needs over the needs of their ill sibling (see Appendix M). The SSCM is a 16-item scale assessing well siblings’ beliefs about focusing on their own needs versus the needs of their ill sibling as well as their ambivalence toward caring for themselves or their ill sibling. There are three subscales of the SSCM: Ambivalence, Balance, and Self-Focus. The items, such as “I try to distance myself
from my ill sibling so that I won’t get physically or emotionally drained” (Self-Focus), “I take the time to assist my ill sibling when he/she needs it” (Balance), and “I feel “caught in the middle” between doing things for myself versus doing things for my ill sibling” (Ambivalence) are rated on a five-point Likert scale (from 1= “Strongly disagree” to 5= “Strongly agree”). Because the three subscales measure different levels of prioritization, they were analyzed separately. Adequate internal consistency have been reported for sibling balance (α=.80), self-focus (α=.73), and ambivalence (α=.78) subscales of the SSCM (Jewell, 1999). Cronbach’s alpha for the SSCM subscales in the current study were .80 (Ambivalence), .82 (Balance), and .77 (Self-Focus).
CHAPTER III. RESULTS

Preliminary Analyses

A series of one-way analyses of variance (ANOVA) examined whether scores on dependent and independent variables differed as a function of gender. Findings indicated that there were no significant gender differences for dependent measures of current caregiving \((F(1,102) = .10; p = .75)\), intentions to care \((F(1, 102)= .34; p = .56)\), stress-related personal growth \((F(1,102) = 3.10, p = .08)\), ambivalence \((F(1,101) = .09; p = .76)\), self-focus \((F(1,101) = 2.40; p = .13)\), and balance \((F(1,102) = 2.41; p = .12)\). Additionally, there were no significant gender differences in respondents’ scores on independent variables of emotional processing \((F(1,102) = .16; p = .69)\) or positive reappraisals \((F(1,102) = 1.53; p = .22)\). Respondents’ scores on personal loss indicated significant gender differences \((F(1,102) = 6.40; p = .01)\), with females indicating higher levels of loss than males \((M= 2.94 \text{ for females}, \ M= 2.53 \text{ for males})\).

A series of one-way analyses of variance (ANOVA) were also performed on the total sample to assess differences in well siblings scores on independent and dependent variables as a function of support group affiliation (dummy-coded). Response options were dummy-coded into two categories, one of which compares no affiliation to affiliation in \textit{either} NAMI or another support group and the other which compares no affiliation to affiliation in \textit{both} NAMI and another support group. For dependent measures, analyses for support group affiliation comparing no affiliation to affiliation in \textit{either} NAMI or another support group indicated that there were no significant differences for current caregiving \((F(1,102) = 2.99, p = .09)\), intention to care \((F(1,102) = .02, p = .88)\), ambivalence \((F(1,101) = .88, p = .35)\), balance \((F(1,102) = 2.5; p = .12)\), self-focus \((F(1,101) = 2.7, p = .10)\), and stress-related growth \((F(1,102) = 2.45, p = .06)\) measures. For independent measures, there were no significant differences found for
emotional processing \( (F(1,102) = .00, p = .99) \) and positive reappraisals \( (F(1,102) = .18, p = .68) \) when comparing no affiliation to affiliation in either NAMI or another support group. Significant differences in support group affiliation comparing no affiliation to affiliation in either NAMI or another support group were found for personal loss \( (F(1,102) = 5.71; p = .02) \).

Surprisingly, well siblings affiliated with only one support group, either NAMI or another group, gave significantly higher personal loss ratings \( (M = 3.11) \) than those who were not affiliated with any support groups \( (M = 2.75) \).

Additionally, for dependent measures, no significant differences were found for support group affiliation comparing no affiliation to affiliation in both NAMI and another support group for intention to care \( (F(1,102) = 3.01, p = .09) \), ambivalence \( (F(1,101) = .12, p = .73) \), balance \( (F(1,102) = 2.31; p = .13) \), and self-focus \( (F(1,101) = .40, p = .53) \). For independent measures, there were no significant differences found for emotional processing \( (F(1,102) = 1.65, p = .20) \) and personal loss \( (F(1,102) = .57, p = .45) \) measures when comparing no affiliation to affiliation in both NAMI and another support group. However, significant differences were found for current caregiving \( (F(1,102) = 4.06, p = .05) \), where those affiliated with NAMI as well as at least one other support group gave significantly higher current caregiving ratings \( (M = 2.61) \) than those who were not affiliated with any support groups \( (M = 2.11) \). Significant differences were also found for stress-related personal growth \( (F(1,102) = 10.47; p = .00) \), where affiliation in both NAMI and another support group \( (M = 1.64) \) conferred significantly higher ratings on stress-related personal growth when compared to the no affiliation group \( (M = 1.09) \). Finally, with regard to independent measures, significant differences were found in positive reappraisals \( (F(1,102) = 9.28; p = .00) \), where well siblings who reported being affiliated with both NAMI
and another family support group ($M = 3.59$) scored significantly higher on positive reappraisals than those with no support group affiliation ($M = 2.81$).

**Descriptive Statistics**

Means and standard deviations for all study measures of interest are presented in Table 3. The mean score for Personal Loss (PLMI-S) fell in the moderate-high range, indicating that loss due to the experience of having a sibling with mental illness was a salient experience among well siblings in the current sample ($M = 2.85$, $SD = .69$). This PLMI-S mean score was significantly different from Stein et al.’s (2005) mean score of 3.30 ($SD = .67$), however, the latter sample ($N=158$) of mental health consumers likely experienced greater loss due to the personal nature of their mental illness, $t(102) = -6.60$, $p < .01$. The mean scores for Emotional Processing ($M = 2.75$, $SD = .88$) and Positive Reappraisals and Growth ($M = 2.89$, $SD = .84$) subscales fell in the moderate to high range. Emotional Processing scores for the current sample did not significantly different from scores obtained by Stanton, Kirk, Cameron, & Danoff-Burg (2000), who tested an undergraduate sample, $t(102) = -1.17$, $p = .25$. Scores on Positive Reappraisals for the current sample of well siblings were significantly higher than scores obtained in a sample of cancer survivors, $t(102) = 3.55$, $p < .01$ (Park, Edmonson, Fenster, & Blank, 2008), but significantly lower than scores obtained by a sample of patients recently diagnosed with cancer, $t(102) = -3.85$, $p < .01$ (Stanton, Danoff-Burg, & Huggins, 2002). This provides support for the notion that the use of coping strategies, such as positive reappraisals, may vary based on the nature and severity of the life stressor, where higher stressors elicit greater use of positive reappraisals. On measures of ill sibling illness severity, scores fell in the moderate to high range for severity ratings ($M = 3.17$, $SD = .80$) and dependence level ratings ($M = 3.32$, $SD = 1.07$).
Well siblings also reported experiencing moderate levels of personal growth due to their experiences with a sibling with mental illness ($M = 1.15$, $SD = .56$), which were significantly lower than scores of personal growth in Jewell’s (1999) sample of well siblings ($M = 1.95$, $SD = .63$), $t(102) = -14.51$, $p < .01$. These differences indicate that the current sample of well siblings reported experiencing less personal growth as a result of having a sibling with a serious mental illness than prior samples.

With regard to measures of caregiving, well siblings scores fell in the moderate range on the Current Caregiving Scale (CCS) ($M = 2.16$, $SD = .80$) and in the high range on the Intention to Care Scale (ICS) ($M = 3.68$, $SD = 1.06$). When compared to Jewell’s (1999) sample, well siblings did not score significantly different on the Current Caregiving Scale $t(102) = .92$, $p = .36$. Jewell (2001) also used the Intention to Care Scale (ICS) ($M = 2.31$, $SD = .78$) on another sample of well siblings, and scores on the ICS from the present study are significantly higher than those for well siblings from this prior sample, $t(102) = 13.19$, $p < .01$. Despite reporting less growth than in prior samples, well siblings in the current study reported the same level of current caregiving and greater intentions to provide caregiving to their ill brother or sister in the future.

Mean scores on the three dimensions of the Self and Sibling Care Measure (SSCM), which assessed well siblings prioritization of their own needs versus the needs of their ill sibling, were as follows: Ambivalence ($M = 3.13$, $SD = .99$), Balance ($M = 3.43$, $SD = .82$), and Self-focus ($M = 3.34$, $SD = .79$). These mean scores for the present sample of well siblings were compared to Jewell’s (1999) sample of well siblings. A series of $t$-tests indicated that the present sample scored significantly higher on only one dimensions of the SSCM, ambivalence, $t(101) = 4.30$, $p < .01$. However, well siblings were not significantly different for self-focus, $t(101) = -.13$,
p = .90, or balance, \( t(102) = 1.06, p = .29 \), when compared to Jewell’s (1999) sample of well siblings.

**Regression Analyses**

A series of six hierarchical multiple regression analyses were conducted to examine the relative contribution of participant demographic and support group affiliation characteristics, perceptions of ill siblings’ dependency and severity of mental illness, self-reported meaning making coping processes, and feelings of personal loss in accounting for variation in reports of sibling caregiving, well siblings self and sibling care commitment priorities, and stress-related personal growth. Regression results are presented in Tables 4 – 6. In each regression analysis, Step 1 consisted of gender, age, and support group affiliation, Step 2 consisted of participants’ perceptions of the ill siblings’ illness severity and dependence, Step 3 consisted of participants’ average scores on emotional processing and positive reappraisals measures, and Step 4 consisted of participants’ average scores on a measure of personal loss adapted for siblings. The criterion variables in each of the separate regression analyses are as follows: (1) participants’ average score on the Current Caregiving Scale (CCS), (2) average score on the Intention to Care Scale (ICS), (3) average score on the Stress-Related Personal Growth scale (SRPG), and (4) average scores on the Self-and-Sibling Care measure (SSCM) Balance subscale, (5) Ambivalence subscale, and (6) Self-Focus subscale.

For each hierarchical regression equation, demographic variables were entered in the first block. These demographic variables were chosen either because scores on study measures differed significantly as a function of that demographic variable (e.g., support group affiliation), because they had relatively high bivariate correlations with the criterion variables (e.g., participant age) or because it is standard practice to partial out their effects (e.g., participant
gender). Sibling illness severity and dependence ratings were entered second because prior research suggests that severity characteristics may be significantly associated with caregiving attitudes and adjustment in family members. Subsequent entry of meaning-related coping processes (e.g., positive reappraisal and emotional processing coping) allowed for exploration of their contribution to the prediction of caregiving, growth, and the prioritization of self and sibling needs above and beyond severity characteristics. Finally, personal loss was entered in the fourth block to determine whether loss experienced due to the mental illness of a sibling is associated with caregiving, growth, and the prioritization of self and sibling needs even after meaning-related coping processes and illness severity have been considered.

**Current Caregiving.** When using current caregiving as the criterion measure, the overall regression model was significant, $F(9, 99) = 4.93, p < .001$ (see Table 4). In Step 1, age ($\beta = .21$, $p < .05$), but not gender or support group affiliation, accounted for 12% of the variance in reports of current caregiving such that older well siblings were more likely to report engaging in current caregiving. In Step 2, the addition of perceptions of ill sibling illness dependence level ($\beta = .34$, $p < .01$), but not illness severity, accounted for 14% of the variance in current caregiving. Participants who perceived that their ill sibling was more dependent were also more likely to report current caregiving. The addition of emotional processing and positive reappraisals in Step 3 did not statistically improve the predication of current caregiving. However, in Step 4, the inclusion of well-siblings perceptions of personal loss ($\beta = .30$, $p < .01$) accounted for 6% of the variance in the prediction of current caregiving. These findings suggest that after accounting for demographic characteristics, perceptions of illness severity and dependence, and meaning making coping processes, well siblings who reported experiencing greater personal loss as a
result of having a brother or sister with serious mental illness were more likely to report engaging in current caregiving.

**Intentions to Care.** When using intentions to care as the criterion measure, the overall model was not significant, therefore, regression statistics for this measure were not examined in detail. Statistical results for this criterion measure can be found in Table 4.

**Stress-Related Personal Growth.** Using stress-related personal growth as the criterion measure, the overall regression model was significant $F(9, 99) = 3.10, p < .01$ (see Table 5). In Step 1, support group affiliation ($\beta = .34, p < .01$), not age or gender, accounted for 15% of the variance in reports of stress-related personal growth. These results suggest that well siblings who reported affiliation with both NAMI and family support groups were more likely to report experiencing growth as a result of coping with the stress of their sibling’s mental illness. The addition of reports of ill sibling illness severity and dependence did not contribute to the prediction of stress-related personal growth. In Step 3, the inclusion of well-siblings reports of positive reappraisals ($\beta = .32, p < .01$), but not emotional processing, accounted for 8% of the variance in reports of stress-related personal growth. After accounting for demographic characteristics and sibling illness severity and dependence, those who reappraised their situation positively were more likely to report experiencing personal growth in response to the stress of having a sibling with mental illness. However, in Step 4, the addition of reports of personal loss by well siblings did not statistically improve the prediction of stress-related personal growth.

**Prioritization of Self and Sibling Care – Balance.** When using balance toward self- and sibling prioritization of needs as the criterion measure, the overall regression model was significant, $F(9, 99) = 2.31, p < .05$ (see Table 6). In Step 1, well siblings demographic characteristics (i.e., age, gender, support group affiliation) did not statistically improve the
prediction of balance with regard to self and sibling care needs. The addition of ratings of illness severity and dependence in Step 2 also did not significantly predict reports of balance. In Step 3, the addition of reports of positive reappraisals ($\beta = .35, p < .01$), but not emotional processing, accounted for 8% of the variance in reports of balance. In Step 4, the inclusion of perceptions of personal loss did not improve the prediction of balance in self and sibling needs. These results suggest that, after accounting for demographic characteristics and ill sibling illness severity and dependence, well siblings who reported making greater positive reappraisals of their situation were more likely to confer balance to their own needs and the needs of their ill sibling. Personal loss, however, did not contribute to the prediction of balance of self and sibling needs.

**Prioritization of Self and Sibling Care – Ambivalence.** When using ambivalence toward self and sibling needs as the criterion measure, the overall regression model was significant, $F(9, 98) = 6.28, p < .001$ (see Table 6). In Step 1, well sibling demographic characteristics including age, gender, and support group affiliation did not statistically improve the prediction of reports of ambivalence. In Step 2, the addition of reports of sibling illness severity and dependence accounted for 7% of the variance in reports of ambivalence, but the contribution of neither severity nor dependence reached significance in predicting reports of ambivalence. In Step 3, the addition of meaning making coping processes, including reports of emotional processing and positive reappraisals, did not make a significant contribution to the prediction of ambivalence. In Step 4, the inclusion of perceptions of personal loss ($\beta = .63, p < .01$) accounted for 27% of the variance in the prediction of ambivalence toward self and sibling needs. These results suggest that well-siblings who perceived that they were experiencing greater personal loss were more likely to report feeling torn between prioritizing their own needs and the needs of their ill sibling.
Prioritization of Self and Sibling Care – Self-Focus. When using self-focus toward self and sibling needs as the criterion measure, the overall model was significant, $F(9, 98) = 2.72, p < .01$ (see Table 6). In Step 1, age ($\beta = -.30, p < .01$) and gender ($\beta = .21, p < .05$), not support group affiliation, accounted for 15% of the variance in reports of self-focus. These results suggest that younger, female well-siblings were more likely to report prioritizing their own needs over the needs of their sibling with serious mental illness. The addition of reports of sibling illness severity and dependence in Step 2 did not make a significant contribution to the prediction of reports of self-focus. Additionally, in Step 3, the addition of reports of meaning making coping processes, including positive reappraisals and emotional processing, also did not statistically improve the prediction of reports of self-focus. In Step 4, the inclusion of perceptions of personal loss ($\beta = -.23, p < .05$) accounted for 4% of the variance in the prediction of self-focus. After accounting for demographic characteristics, perceptions of illness severity and dependence, and meaning making coping processes, well siblings who were experiencing less personal loss were more likely to report prioritizing their own needs over the needs of their ill sibling.
CHAPTER IV. DISCUSSION

The present study examines the reports of 103 well siblings of adults with serious mental illness. The research investigates well siblings’ perceptions of their ill siblings’ illness severity as well as their own meaning making coping efforts, personal loss, stress-related growth, caregiving responsibilities, and self-care and sibling care priorities. Main research questions examine the relative contribution of well siblings’ demographic factors, ill sibling illness severity levels, meaning-making coping processes (positive reappraisals, emotional processing), and personal loss in describing variation in reports of current and future caregiving, growth, and self and sibling prioritization of needs. Specifically, this research aims to clarify the role of personal loss in accounting for unique variations in well sibling caregiving experiences, stress-related growth and perceptions of the self and sibling care commitments after partialling out demographic, illness severity, and meaning making variables.

Findings from the present study show that perceptions of personal loss among well siblings significantly predict reports of current caregiving as well as ambivalence and self-focus with regard to self-care and sibling care. Personal loss appears less relevant when considering reports of stress-related personal growth and balance regarding self and sibling needs. Instead, meaning making coping efforts emerge as relevant to these constructs, and significantly account for the largest amount of unique variance in reports of growth and balanced self and sibling care commitments. Specifically, positive reappraisals significantly predict balance with regard to self and sibling care as well as perceptions of stress-related personal growth. These effects of personal loss and meaning making emerge when partialling out the effects of demographic and illness severity factors.
Research Question #1: The Effect of Demographic and Illness Severity Characteristics

Based on evidence from previous research, certain well sibling demographic characteristics as well as ratings of sibling illness severity were expected to have predictive value when considering patterns of growth, caregiving, and self and sibling care commitments. Specifically, siblings who were older, female, and who reported greater support group affiliation and higher ratings of sibling illness severity were hypothesized to also report higher scores on measures of current caregiving and intentions for caregiving and greater stress-related growth. Younger age was expected to be associated with self-focus toward self and sibling care needs.

Caregiving. In assessing the effect of age, gender, and support group affiliation on current caregiving, only the age of well siblings was predictive of current caregiving levels. Older well siblings reported engaging in greater levels of current caregiving, which is consistent with existing literature that suggests that caregiving responsibilities increase as siblings and parents age and parents begin to express needs for assistance in caregiving (Lefley & Hatfield, 1999). However, the lack of significant findings for gender and support group affiliation contrast with prior studies that suggest that greater support group affiliation and female gender predict greater current caregiving (Jewell, 1997). These results should be interpreted with caution, given the overrepresentation of females and siblings unaffiliated with support groups. The lack of caregiving differences found may indicate that well siblings facing similar caregiving situations chose to participate, regardless of their support group affiliation status or gender. Gender and support group affiliation differences in well siblings’ reports of caregiving should be further explored with samples of siblings that have equal numbers of men and women as well as equal numbers of siblings who are affiliated and unaffiliated with support groups.
When considering the addition of illness severity factors to the prediction of current caregiving, the current study found that perceptions of greater dependence due to mental illness, but not illness severity itself, are associated with greater engagement in current caregiving. Beyond illness severity alone, dependence level appears to tap needs for assistance among brothers and sisters with mental illness that implores well siblings to take on caregiving responsibilities. Perceptions among well siblings that their brother or sister’s mental illness is severe may not influence caregiving decisions unless well siblings perceive that the serious mental illness has had a noticeable impact on daily functioning that translates into greater dependence on assistance from others.

Intentions to provide caregiving in the future were not associated with any demographic or illness severity factors. Given the relatively young age of the current sample ($M = 38.9$, $SD = 13.8$), it may have been difficult for well siblings to accurately gauge their future caregiving and support plans. Well siblings also reported relatively high intentions for future caregiving ($M = 3.68$, $SD = 1.06$) compared to current caregiving engagement ($M = 2.16$, $SD = .80$), which may have reduced the effect of specific demographic and illness severity factors on the prediction of intentions to care.

*Growth.* Although gender and age were expected to be associated with reports of stress-related personal growth among well siblings, support group affiliation was the only demographic characteristic that was predictive of growth. Participation in mental illness support groups, such as the National Alliance on Mental Illness (NAMI), as well as in online sibling support and advocacy groups may result in greater ability to reinterpret the stress caused by mental illness in the family as an opportunity for growth and positive change. Surprisingly, in a similar study conducted by Jewell (1999), NAMI membership was not predictive of stress-related personal
growth, and affiliation with NAMI was negatively associated with reports of growth among well siblings. Given that the current sample was categorized into levels of affiliation that included other support groups in addition to NAMI (i.e., no affiliation, affiliation with either NAMI or another support group, affiliation with both NAMI and another support groups), affiliation status measured in this way may have been better able to tap adaptive outcomes associated with greater levels of support group affiliation, including stress-related personal growth.

The addition of illness severity and dependence did not significantly predict reports of stress-related personal growth in the present study. Prior research findings which suggest that factors tapping the stressfulness of the negative event, such as a loved one’s mental illness severity, may be predictive of stress-related growth were not supported (Schaefer & Moos, 1992). Although perceptions of greater illness severity are positively associated with greater personal loss among well siblings in the current study, it appears that well siblings potential for growth is unaffected by their perceptions of the severity of mental illness or of the dependence caused by mental illness. Stress-related personal growth may be a unique characteristic of well siblings who are able to transcend the losses and stressors associated with mental illness in the family through the use adaptive coping mechanisms and with assistance from mental illness support groups.

*Self and Sibling Care.* The current research aims to clarify and expand the self and sibling care construct by predicting the distinct subscales of self-focus, ambivalence, and balance toward self-care and sibling care commitments. In the current study, only gender is predictive of self-focus toward self-care and sibling care priorities, in which female gender is predictive of endorsements of self-focus. This result may be biased by the skewed nature of the current sample, in which approximately 80% of the respondents were female. However, given the
association of caregiving labor with women’s traditional gender roles, females are more likely to be faced with caregiving responsibilities and may be more likely to experience caregiver stress than men (Neufeld & Harrison, 2010). Therefore, it is perhaps not surprising that, as the influence of traditional gender roles diminishes and women continue to take on greater responsibilities outside of the home, women would endorse a priority toward self-focus when considering self and sibling care needs. As expected, younger age is also predictive of a self-focused attitude toward self and sibling care priorities. From a lifespan development perspective, younger well siblings may not be faced with greater caregiving responsibilities, as parents are more likely to be well enough at this stage to care for their children with mental illness without asking for additional support from well siblings (Hatfield & Lefley, 2005; Jewell, 1999). This hypothesis is supported by evidence from the current dataset, which shows that older age is associated with and predictive of greater current caregiving. Additionally, younger well siblings may face greater difficulty adjusting to growing financial and time constraints from their own families and careers, which may impel preferences for self-care over sibling care (Earl, 2005; Hatfield & Lefley, 2005; Marsh, 1998). This hypothesis is supported when examining the associations between financial and time constraints and age in the current dataset (see Table 3), where younger age was associated with greater financial and time constraints.

The current study does not provide clear evidence of a consistent association between sibling illness severity ratings and self and sibling care commitments. However, when considered together, ratings of severity and dependence confer significance to the prediction of ambivalence toward self and sibling care, though neither dimension of severity is alone significant. It appears that well siblings’ perceptions of both greater severity and dependence regarding their ill sibling are predictive of greater ambivalence toward self and sibling care. Well
siblings may be torn between self-care and sibling care given their awareness of the gravity of their ill siblings’ need for care. While prior research suggests that the majority of adult siblings feel a sense of lifetime obligation toward their ill siblings (Marsh, et al., 1993), only 18% of the current sample identified themselves as the primary caregiver for their ill sibling. Thus, well siblings may experience ambivalence because they believe they should be providing more assistance than they are currently providing to their ill sibling, given the seriousness of this sibling’s condition. In contrast, severity and dependence ratings are not associated with balanced or self-focused attitudes toward self and sibling care, both of which appear to indicate a more resolved attitude toward decision-making about caregiving.

Research Question #2: The Contributions of Personal Loss and Meaning Making

The present study examined the relative contribution of personal loss scores in accounting for variation in scores on measures of caregiving, growth, and the prioritization of needs beyond that of well sibling demographic characteristics, perceptions of illness severity of siblings with mental illness and meaning-related coping processes. Scores on measures of meaning making coping (i.e., positive reappraisals, emotional processing) were expected to statistically predict a larger portion of the variance in stress-related growth, caregiving, and the prioritization of self versus sibling needs than demographic and severity factors. However, personal loss was hypothesized to predict the largest variance in these criterion measures, above and beyond the contributions of meaning-related coping processes.

Caregiving. The results from the current study suggest that meaning-making coping efforts do not significantly contribute to the prediction of current caregiving or to intentions to provide care in the future. Well siblings who participate in caregiving activities may do so out of a sense of obligation to family or because parents are no longer able to provide care. The use of
coping strategies, such as positive reappraisals and emotional processing, may not be necessary given that most siblings already feel a sense of lifetime responsibility to help take care of their ill siblings (Marsh, 1993, 1997). Additionally, although nearly all participants (92%) reported engaging in at least one caregiving activity, the majority of respondents indicated that they were not highly involved in these activities. This lack of involvement among well siblings may indicate that their sibling’s mental illness has not yet had a great impact on their adult lives and, therefore, may not have been appraised as being stressful enough to shatter or disrupt global meaning systems. According to Park (2008), without a discrepancy forming between situational and global meaning systems in response to a stressful event (e.g., a siblings’ mental illness), meaning making coping efforts are not initiated. The lack of association between meaning making coping processes and current caregiving may also indicate that well siblings use other forms of coping to manage the caregiving demands of their sibling’s mental illness (Friedrich, Lively, & Rubenstein, 2008; Blasko, 2007).

Although the prediction of intention to care was nonsignificant, it is notable that lower endorsement of emotional processing by well siblings is associated with greater intentions to provide caregiving. This association suggests that well siblings who reported intentions to provide care in the future may not have fully processed the emotional implications of the caregiving role.

With the addition of personal loss the prediction of current caregiving, the present findings suggest that greater loss experiences are associated with greater current engagement in caregiving. Loss experiences appear to be more salient among well siblings who are active caregivers within their family of origin. Although the direction of causality is unclear given the cross-sectional design of the current study, it appears that well siblings who engage in caregiving
are more likely to have experienced disturbances to their sense of identity as well as to their sense of their sibling’s former self, to their roles and routines, former relationships with others, and expectations for the future. Given the personal loss has been found to be positively associated with self-reports of loneliness, psychological symptoms, and problems with alcohol (Stein, et al., 2005), these siblings may be under the greatest psychological distress in association with the challenges of their caregiving activities. It is also be possible that these siblings have not yet received adequate services to prepare them for the stressors associated with the caregiving role and, thus, have the greatest need for support from professionals, parents, and advocacy groups in taking on caregiving responsibilities within their family of origin.

**Growth.** Among the meaning making coping efforts assessed in the current study, findings suggest that positive reappraisals are positively associated with and predictive of experiences of stress-related growth. In contrast, emotional processing did not significantly contribute to the prediction of growth. These results suggest that the ability to reappraise a sibling’s mental illness in a positive light may help restore alignment between global and situational meanings and, thus, predict the experience of stress-related growth (Carver et al., 1989). Prior research not only supports the notion that positive reinterpretations of stressful life experiences may act as determinants of stress-related growth (Taylor, 1983), but also suggests that the experience of growth may have implications for well siblings’ caregiving and support role. In a study examining expectations about future caregiving roles among well siblings of adults with schizophrenia, those who felt a felt a greater sense of personal growth through coping with their sibling’s illness were more likely to endorse future expectations to provide instrumental support to their ill sibling than those who experienced fewer gains (Smith, Greenberg, Seltzer, 2007). In contrast to measures of caregiving or self and sibling care
prioritization (which assesses beliefs about caregiving involvement) alone, personal growth may be more directly tied to how siblings’ process or cope with mental illness in the family context (Jewell, 1999). Prior studies have also found a positive association between positive reappraisals, growth, and life meaningfulness (Park, et al., 2008). Personal growth may tap siblings broad experiences with mental illness in the family and may be more likely to elicit efforts at positive reappraisals and meaning making coping, whereas caregiving and self and sibling care may represent only a small fraction of well siblings’ experiences with their brother or sister (Jewell, 1999), from which deriving meaning may be more difficult due to increased distress, loss, or diminished quality of life.

The addition of personal loss did not confer additional significance to the prediction of stress-related personal growth. Personal loss may indicate that well siblings are experiencing difficulty coping with or finding meaning from their siblings’ mental illness, making it more difficult for growth experiences to occur. Devastating loss experiences due to mental illness may also make it difficult for well siblings to even consider reinterpreting mental illness as a potential growth experience. These findings are consistent with prior research on personal loss due to mental illness, which showed that reports of personal loss were unrelated to reports of personal growth among individuals coping with psychiatric disability (Stein et al., 2005).

*Self and Sibling Care.* As Jewell (1999) points out, there are several plausible yet rarely investigated factors that may lead to well siblings’ self and sibling care attitudes. Given the complex nature of this construct and the array of factors that likely affect decision making around self-care versus sibling care, the present study empirically tested the role of personal loss and meaning making coping in predicting these commitments after accounting for the effect of age, gender, support group affiliation, and illness severity. It appears as though the attitudes of
balance, self-focus, and ambivalence toward self and sibling needs are predicted by either perceptions of meaning making coping or personal loss but not by the experience of both simultaneously.

Meaning making coping, such as emotional processing and positive reappraisals, contributed to the prediction of balance with regard to prioritization of self and sibling needs, which was not significantly predicted by the addition of personal loss. That is, well siblings who reported higher levels of positive reappraisals also had greater endorsement of balanced perspective toward self-and-sibling-care commitments. Positive reappraisals appear more relevant to a balance attitude toward self and sibling care than emotional processing, which does not seem to uniquely account for variance in this outcome. Well siblings who report engaging in meaning making coping, such as positive reappraisals, may also be buffered against the potential effects of loss on the development of a balanced attitude toward self and sibling care. Positive reappraisals may lead to a re-evaluation of the traumatic experience of mental illness in the family in way that enables one to give back to the family of origin, in this case, the ill sibling and their caregiving and support needs. In contrast, meaning making coping efforts by well siblings are not associated with ambivalent or self-focused attitudes toward self and sibling care, suggesting that well siblings with these attitudes may not have the resources available to cope with the demands or expectations of the sibling caregiving role or may not see it as a meaningful role. As suggested previously, self and sibling care attitudes that are associated with experiences of loss (e.g., ambivalent attitudes, as suggested by the current study), may represent only a small fraction of well siblings’ experiences with their brother or sister (Jewell, 1999), from which deriving meaning may be more difficult.
In the present study, perceptions of personal loss are significantly related to perceptions of ambivalence and self-focus toward self and sibling care priorities, but are not related to a balance attitudes toward self and sibling care. After accounting for meaning making, illness severity, and demographic factors, greater perceptions of personal loss predict greater ambivalence toward self-and-sibling care commitments. In contrast, using the same hierarchical regression model, lower ratings of personal loss were significantly predictive of greater self-focus toward self and sibling care commitments.

It appears that loss may be crucial to the development of ambivalent or detached sibling commitment styles. Those who report greater loss with regard to their future, former self, former relationships, and roles and routines appear to be torn about whether to be involved in helping to address their sibling’s needs (Stein, et al., 2005; Dixon, 1997). Given that prior research has characterized sibling relationships as combining “the affective intensity and reciprocity of peer relationships with many of the complementary processes associated with parent-child relationships” (Hetherington & Clingempeel, 1992; Dunn, 1983), siblings may display both empathic and antagonist behavior toward one another. Well siblings may remember the way their sibling used to be before the onset of illness or may have witnessed the functioning deficits that often emerge in cases of serious mental illness, both of which may lead to feelings of obligation to help address ill siblings’ needs. At the same time, these memories may be offset by feelings of loss and resentment related to the time and energy demands of their sibling’s mental illness, which make it more difficult for well siblings to justify providing additional caregiving to their ill sibling. Well siblings may feel a deep sense of personal loss because their sibling demanded much of their parents’ attention when the well sibling also required parental attention (Jewell, 1999). These demands for support and attention may have continued throughout sibling
development, even when well siblings became obligated to provide attention to the needs of their own children, and may further contribute to feelings of loss in adulthood. These competing sources of loss for oneself and one’s ill sibling seem to contribute to ambivalence about whether or not it is justifiable to provide caregiving to a sibling in addition to oneself or one’s spouse and children.

The finding that lower ratings of personal loss are associated with a greater self-focused attitude toward self and sibling care suggests that the fewer experiences of loss may reduce well siblings’ feelings of obligation to provide sibling care. These siblings may not feel as many losses because their ill siblings’ mental illness demanded attention at time when they did not report significant family constraints or compete for parental attention. Other adult well siblings may feel justified in focusing on themselves or excluding their ill siblings’ from their lives if they perceive that excessive attention was placed on their ill sibling during childhood or adolescence (Jewell, 1999). Furthermore, for well siblings who did not have a close relationship with their ill sibling prior to illness onset or for those who feel justified in prioritizing their own family’s needs (Smith & Greenberg, 2007), feelings of loss may not emerge, making it easier for these siblings to adopt a self-focused attitude toward self and sibling care.

**Study Limitations**

Generalizability of the present findings is unclear due to the low level of current sibling caregiving reported (only 18% of participants identified themselves as primary caregivers) and the non random sampling methods used. An additional limitation is that the study used a relatively small, predominately female, Caucasian sample of well siblings. Recruitment methods, which sampled from online message boards for siblings of adults with serious mental illness and from NAMI chapters, may have resulted in a sample where the most active siblings
are over-represented. The sampling design also does not allow for thorough consideration of the role of parental figures on the caregiving expectations of well siblings. The use of the term “well siblings” may not fully capture the distress level of participants, given that 23% of participants reported some form of depression and another 19% reported experiencing some other mental health problem. Results should be interpreted with caution given the large number of independent variables measured and the relatively small sample size of the data set.

The cross-sectional nature of the study does not allow for examination of the causative direction of associations between personal loss, meaning making coping, and experiences of caregiving, growth, and self and sibling care commitments. Future research should strive for a larger sample size, more ethnic, racial, and religious minorities, and longitudinal research designs which allow for the examination of the causality among variables and of the variations in sibling caregiving, loss and growth across the lifespan.

*Implications for Future Research, Practice, and Community Action*

Mental health providers, researchers, and policy makers should broaden their definitions of the family support network to include adult siblings of individuals with serious mental illness. The findings of the present study also highlight the importance of personal loss due to mental illness as a construct for further investigation which has compelling implications for clinical and community intervention. Relatives of individuals with mental illness, including well siblings, need to be understood as having experienced a complex loss. In order to facilitate collaboration between family members and the mental health service system, professionals should be aware of research that captures the complex and uncomfortable emotional experiences of families of adults with serious mental illness, including feelings of anger, guilt, and chronic grief (Jones, 2004). Longitudinal research approaches are needed to clarify the changing role of loss and
coping in caregiving and growth experiences, particularly as ill siblings’ transition from relapse to recovery. Additional qualitative research and psychometric analysis is needed to develop objective measures of loss that may shed further light on the experience of loss due to mental illness.

In addition to the implications of personal loss, meaning-making coping was associated with adaptive outcomes (e.g., growth) among well siblings in response to the experience of mental illness in the family. Meaning-making coping efforts, specifically positive reappraisals, were predictive of stress-related personal growth and a balanced attitude toward self and sibling care. The present study should be considered preliminary rather than conclusive, and results are meant to serve as a catalyst for future research on meaning making. Future research should not only longitudinally investigate the causal factors associated with the development of positive reinterpretations among well siblings, but should also further examine the outcomes associated with a balanced attitude toward self and sibling care, which may impact sibling relationship quality, caregiving satisfaction, and psychological well-being. Much of the research on meaning making has focused on the shattering of previously held beliefs and on discrepancies between global and situational meaning that form in response to a loss or stressful event (e.g., Gluhoski & Wortman, 1996, Park, 2008). However, it is unclear whether this definition of the meaning making construct is applicable when assessing serious mental illness as stressful life experience. Given that emotional processing has been included in prior studies of meaning making, yet its role in various outcome measures was not substantiated, it is unclear whether emotional processing has implications for meaning making in response to mental illness. As Park (2008) highlights, meaning making coping efforts, including emotional processing, may be variably efficient in reducing discrepancies or in leading to adaptive outcomes. A more comprehensive
model of meaning making coping which clarifies the full range of other potential meaning making coping processes and their effects is needed, particularly for studies on serious mental illness.

The finding that greater levels of current caregiving are associated with a higher degree of personal loss have implications for mental health practitioners who work with family members directly or with consumers who receive support and caregiving from family members. Given that family dialogue about future sibling caregiving may not occur without prompting, it may be worthwhile for mental health professionals or support group facilitators to teach consumers and parents effective ways to communicate needs to well siblings (Lefley & Hatfield, 1999). Encouraging involvement from siblings early in treatment help to alleviate long-term anxiety about the caregiving role and help to promote feelings of stability and support among consumers (Earl, 2005). Increased understanding of sibling needs, expectations, coping strategies are also imperative to ensure appropriate future support that includes a smooth transition of caretaking from parents to siblings.

The need for assistance from practitioners and community programs has been acknowledged by well siblings in prior research (Hatfield & Lefley, 2005). In a sample of 60 well siblings, 48% of siblings indicated a desire for sibling support groups to address future caregiving and 46% expressed interest in written material on mental illness and coping. Half of siblings in Hatfield and Lefley’s (2005) sample also acknowledged a desire for better understanding among providers and parents regarding the stressors siblings face, and 41% indicated that they would benefit from programs designed to help parents formulate future plans for their sibling with serious mental illness. These findings provide evidence that mental health agencies, support groups, and professionals should provide services for and build alliances with
adult well siblings, particularly when governmental resources are not adequate to address the needs of the mentally ill or when parental caregivers age and become incapable of providing support and caregiving (Hatfield & Lefley, 2005; Horowitz & Reinhard, 1995). Adequate community resources for well siblings and other caregivers are needed to ensure that they are not overwhelmed by caregiving demands or forced to cope with stressors beyond what is considered clinically healthy. Given that support group affiliation was predictive of stress-related personal growth in the current study, greater access to community resources and advocacy networks for well siblings may also increase their ability to cope with and derive meaning from the ongoing challenges associated with mental illness in the family.

Overall, results underscore the potential importance of involving well siblings in treatment planning and in family support groups. Provider outreach to families could help siblings obtain greater knowledge of their brother or sister’s mental illness, including how to access treatments and resources, which would help families to better advocate for themselves as a unit (Davidson, Tondora, Staeheli, O’Connell, Frey, & Chinman, 2006). Furthermore, better understanding of the relationships of loss and coping to caregiving, stress-related growth, and self and sibling care priorities is vital for the creation and implementation of effective family-based services. Although services geared specifically toward well siblings are sparse, a better understanding of the loss and coping experiences of well siblings may help to create community interventions that enhance family strengths and increase valued social roles for siblings.

Conclusion

Systematic examination of siblings without disabilities as sources of informal care is particularly timely and represents an issue of importance for persons with mental illness, their families, and policy makers (Lohrer, Lukens, & Thorning, 2006; Greenberg et al., 1997, 1999).
Findings suggest that personal loss was the strongest predictor of both current caregiving among well siblings as well as ambivalence about how to simultaneously address personal needs and sibling needs. Well siblings’ meaning making efforts, specifically their positive reappraisals, predicted stress-related growth and a balanced perspective toward involvement in caregiving. Although further research is necessary to test the reliability of these effects, the impact of personal loss and meaning making on caregiving behaviors, caregiving attitudes, and growth experiences appears to have powerful implications for clinical and community intervention.
REFERENCES


APPENDIX A: SAMPLE RECRUITMENT EMAIL

Dear [Facilitator/NAMI Chapter Affiliate],

I enjoyed speaking with you on the phone today. Thank you for your interest in my research and for your willingness to disseminate my questionnaire to members of your [support group/chapter listserv]. I am interested in surveying siblings of individuals with serious mental illness, or connecting with parents and other family members who may be able to connect me with siblings. Below is the information that can be disseminated to members of your [support group/listserv]. Feel free to contact me if you have any additional questions.

Thank you for your assistance,

Jaclyn Leith

Graduate Student, Clinical Psychology

Bowling Green, OH 43403

(419) 372-4597

jleith@bgsu.edu
APPENDIX B: RECRUITMENT POSTING FOR ONLINE COMMUNITIES

Study Opportunity for Siblings of Persons Diagnosed with a Mental Illness:

My name is Jaclyn Leith, and I am a graduate student in Clinical Psychology at Bowling Green State University in Ohio. I am conducting a research study to understand how siblings cope and make meaning from the experience of having a brother or sister with mental illness. The results of the study will also be used to help better understand how siblings feel about caregiving and how they prioritize their own needs and their siblings’ needs.

This study involves completing an online questionnaire at a time and place that is convenient for you. I estimate that it will take you no longer than 20-30 minutes to complete this survey. For your participation, you have the option of being entered in a raffle to win one of three $75 cash prizes.

This brief study can be accessed online at: http://psych.bgsu.edu/siblingsurvey.htm

If you are a brother or sister of a person with a serious mental illness, please consider participating in this important study by clicking on the link below or by contacting me. If you are a parent or family member, please consider sharing this message with the sibling(s) of your relative with mental illness.

You will be asked to give your informed consent before beginning the survey. All responses are strictly confidential, and results from this survey will only be reported in aggregate form. Participation in this study is strictly voluntary, and you may withdraw from participation at any time.

Any questions or comments about this survey can be directed to Jaclyn Leith at jleith@bgsu.edu or by calling 419-372-4597. Please contact me if you would like to complete the survey on paper forms. This research study has been approved by the Institutional Review Board at Bowling Green State University.

Thank you in advance for your help!

Jaclyn Leith
Department of Psychology
Bowling Green State University
Bowling Green, OH 43403
jleith@bgsu.edu
IRB Approval #: #H10T153GE7
APPENDIX C: HSRB APPROVAL LETTER AND INFORMED CONSENT WEBPAGE

December 10, 2009

TO: Jaclyn Leith
Psychology

FROM: Hillary Harms, Ph.D.
HSRB Administrator

RE: HSRB Project No.: H10T153GE7

TITLE: Well Siblings of Adults with Serious Mental Illness: The Role of Meaning Making in Caregiving and in the Prioritization of Sibling Needs

You have met the conditions for approval for your project involving human subjects. As of December 10, 2009, your project has been granted final approval by the Human Subjects Review Board (HSRB). This approval expires on November 30, 2010. You may proceed with subject recruitment and data collection.

The final approved version of the consent document(s) is attached. Consistent with federal OHRP guidance to IRBs, the consent document(s) bearing the HSRB approval/expiration date stamp is the only valid version and you must use copies of the date-stamped document(s) in obtaining consent from research subjects.

You are responsible to conduct the study as approved by the HSRB and to use only approved forms. If you seek to make any changes in your project activities or procedures (including increases in the number of participants), please send a request for modifications immediately to the HSRB via this office. Please notify me, in writing (fax: 372-6916 or email: hsrb@bgsu.edu) upon completion of your project.

Good luck with your work. Let me know if this office or the HSRB can be of assistance as your project proceeds.

Comments/ Modifications:
Stamped original is coming to you via campus mail. Please add text equivalent to the HSRB approval/expiration date stamp to the "footer" area of the electronic informed consent.

c: Dr. Catherine Stein

Research Category: EXPEDITED #7

Post-it Fax Note 7071 Date 2.009/0

[Fax note content]

RECEIVED TIME DEC. 10, 11:02AM PRINT TIME DEC. 10, 11:06AM
You are invited to participate in a study about how individuals adapt to the challenges of having a brother or sister with mental illness. The study requires no special knowledge about mental illness; rather the project is interested in how siblings of individuals with serious mental illness view their family involvement and needs.

Your participation will involve completing an online survey about your experiences having a sibling with mental illness and how this experience has affected you. You will also be asked some background information questions that we will use to describe our participants (e.g., age, gender). The survey should take about 45 minutes to complete.

The research study is being conducted by Jaclyn Leith, a doctoral student in Psychology, with the support of Dr. Catherine Stein, a professor in the Department of Psychology at Bowling Green State University.

You are eligible to participate if you are at least 18 years old, and have at least one sibling who has a serious mental illness. You are encouraged to participate in the research regardless of your current level of contact with your ill sibling.

Your responses to the survey are confidential. At the end of the survey, you will be redirected to a new webpage that asks for your name and contact information so that you can be entered into a drawing for $75. Your name and contact information will not be directly linked to your survey responses. Completion of the contact information form is necessary in order to be eligible to participate in the drawing for $75.

The benefits of participating in this project include gaining a better understanding of the ways that individuals cope with the experience of having a sibling with mental illness. You may also learn more about your views about having a sibling with mental illness and how it has affected you. Additionally, by completing the survey and providing your contact information, you will be entered into a drawing for $75. Three participants whose names are selected at random from a list of all participants will receive $75 each.

The anticipated risks to you are no greater than those normally encountered in daily life. The only risk is that people sometimes feel slightly uncomfortable answering some questions. It is important for you to know that you may skip any questions that make you feel uncomfortable.

It is important for you to know that your participation in this study is completely voluntary. Please note that you may stop participating in the survey at any time. You may click on the X at the top right hand corner of your computer window to exit the online survey. You are also free to skip any questions you do not want to answer. Additionally, your responses will not be saved until you click the “Submit” button at the end of the online survey. If you exit and then decide later that you would like to participate, you can visit the web address posted in the study announcement or contact the researcher.

To make sure that your responses are kept confidential, the information you provide will be stored in a database on a secure server. It will be accessed only by the investigator. Again, no names will be associated with survey responses. When the survey data and contact information data are accessed from the secure server, each will be stored separately on password-protected databases.
Since some employers use software that tracks websites visited and keystrokes made you may wish to complete the questionnaire on a home or public computer in order to safeguard your confidentiality.

Since the internet is not 100% secure in terms of privacy, please remember to not leave the partially completed survey open or unattended if completing it on a public computer, and to clear the browser page history and cache when finished with the survey.

I hope to publish an article summarizing the overall results of this study, but no one person’s answers will be presented – only a summary of data from many participants.

In addition, if you have any questions about the study, you may contact the principal investigator:

- Jaclyn Leith, Doctoral Student in Psychology, Psychology Department, Bowling Green State University, (419) 372-4597, jleith@bgsu.edu

You may also contact the Chair of Human Subjects Review Board at Bowling Green State University, (419) 372-7716 (hsrb@bgnet.bgsu.edu), if any problems or concerns arise during the course of the study.

Your completion of this survey indicates your voluntary consent to participate in this research investigation. You may refuse to participate in this investigation or withdraw your consent and discontinue participation in this study. If you are eligible to participate and wish to give your consent and continue, please select the response option below and click on the “Next” button; you will then be directed to the survey. If you prefer not to participate, please close this browser window.

- I have been presented with and have read the statement of risks and benefits of participating in this project and I agree to participate. I certify that I meet the eligibility requirements for this study.

APPENDIX D: DEMOGRAPHIC INFORMATION

Please fill in the blanks with the appropriate information or indicate the response that best applies to you.

1. Your Gender:
   (0) Male
   (1) Female

2. Your Age (in years): _____

3. Your Marital Status:
   (1) single / never married
   (2) married / remarried
   (3) living, as if married, with a partner
   (4) separated / divorced
   (5) widowed

4. How many children do you have? (Include natural, adopted, step, and foster children) _____

5. Which of these groups best describes you:
   (1) Asian
   (2) African-American (or Black)
   (3) Caucasian (or White)
   (4) Hispanic
   (5) Other, please specify: _____________________

6. Your highest level of education:
   (1) pre-high school
   (2) some high school
   (3) high school graduate
   (4) some college or technical school
   (5) college graduate (4 year degree)
   (6) advanced degree (graduate training)

7. Are you currently working for pay:
   (1) full-time
   (2) part-time
   (3) retired
   (4) disabled
   (5) unemployed
   (6) other _______________________

8. What is your approximate annual income, before taxes, from all sources:
   (1) less than $20,000  (4) $41,000 - $50,000  (7) $71,000-$80,000   (10) over $100,000
   (2) $21,000-$30,000  (5) $51,000-$60,000  (8) $81,000-$90,000
   (3) $31,000-$40,000  (6) $61,000-$70,000  (9) $91,000-$100,000
9. In what state do you currently live:

(1) Alabama
(2) Alaska
(3) Arizona
(4) Arkansas
(5) California
(6) Colorado
(7) Connecticut
(8) Delaware
(9) Florida
(10) Georgia
(11) Hawaii
(12) Idaho
(13) Illinois
(14) Indiana
(15) Iowa
(16) Kansas
(17) Kentucky
(18) Louisiana
(19) Maine
(20) Maryland
(21) Massachusetts
(22) Michigan
(23) Minnesota
(24) Mississippi
(25) Missouri
(26) Montana
(27) Nebraska
(28) Nevada
(29) New Hampshire
(30) New Jersey
(31) New Mexico
(32) New York
(33) North Carolina
(34) North Dakota
(35) Ohio
(36) Oklahoma
(37) Oregon
(38) Pennsylvania
(39) Rhode Island
(40) South Carolina
(41) South Dakota
(42) Tennessee
(43) Texas
(44) Utah
10. Are you currently a: (circle all that apply)
   (1) member of NAMI (local, state, or national)
   (2) member of a support group
   (3) none of the above
   (4) other, please specify: ________________________

11. Overall, how would you rate your involvement in family member and sibling support and
advocacy groups?
   (1) not involved
   (2) a little involved
   (3) somewhat involved
   (4) very involved

12. Your religious preference:
   (1) Protestant/Other Christian
   (2) Catholic
   (3) Jewish
   (4) Muslim
   (5) Buddhist
   (6) Hindu
   (7) None/No Affiliation
   (6) Other, please specify: ________________________

13. Overall, how religious are you?
   (1) not at all religious
   (2) a little religious
   (3) somewhat religious
   (4) very religious

14. Have you ever been diagnosed with a mental health problem?
   (1) Yes (Go to 15)
   (2) No (Skip 15. Hit “Next” to skip to the next page)

15. If yes to item 14, what was the primary diagnosis for your mental health problem?
   ________________________________________
These are some background questions about your sibling with mental illness. Please fill in the blanks with the appropriate information or indicate the response that best describes your sibling.

1. Your ill sibling's Gender:
   (1) Male
   (2) Female

2. Your ill sibling's Age (in years):_________

3. Your ill sibling's marital status:
   (1) single / never married
   (2) married / remarried
   (3) living, as if married, with a partner
   (4) separated / divorced
   (5) widowed

4. How many children does your ill sibling have? (Include natural, adopted, step, and foster children)____

5. Your ill sibling's highest level of education:
   (1) pre-high school
   (2) some high school
   (3) high school graduate
   (4) some college or technical school
   (5) college graduate (4 year degree)
   (6) post graduate training

6. Your ill sibling's employment status:
   (1) full-time
   (2) part-time
   (3) retired
   (4) disabled
   (5) unemployed
   (6) other_______________________

7. Which of the following best describes your ill sibling’s current financial situation?
   (1) Not enough money to make ends meet
   (2) Just enough money to pay for the things they need
   (3) A little money left over
   (4) More than enough money left over

8. What is your ill sibling's current living situation?
   (1) lives independently in house or apartment with no formal supervision
   (2) lives with a family member
   (3) lives in house or apartment with formal supervision
   (4) lives in a group home / community residential care facility
(5) lives in an inpatient psychiatric facility
(6) homeless
(7) correctional facility (i.e. jail or prison)
(8) other, please specify:________________

9. How far does your ill sibling live from you?
(1) within a 1 hour drive (about 0-50 miles)
(2) within a 1 to 2 hour drive (51-100 miles)
(3) within 1/2 day's drive (101-300 miles)
(4) within 1 day's drive (301-1000 miles)
(5) not easily reached by car (over 1000 miles)

10. What do you believe is your ill sibling's current primary psychiatric diagnosis?
(1) schizophrenia
(2) schizoaffective disorder
(3) depression
(4) bi-polar / manic-depression
(5) a personality disorder
(6) unknown
(7) other, please specify:______________________________

11. In regard to your answer to the above question, how long has your ill sibling been diagnosed?
(1) less than 1 year
(2) 1-3 years
(3) 3 - 5 years
(4) 5 - 10 years
(5) 10-20 years
(6) More than 20 years

12. Does your ill sibling have a primary therapist, case manager, or social worker who sees them on a regular basis?
(1) Yes
(2) No

13. How many times has your ill sibling been hospitalized? (Han, 1995)
(1) Not at all
(2) 1 to 2 times
(3) 3 to 5 times
(4) 6 to 10 times
(5) More than 10 times

14. How serious or severe would you say your sibling's illness is right now?
(1) not at all serious
(2) a little serious
(3) somewhat serious
(4) very serious

15. How would you describe your sibling’s current level of independence? (Han, 1995)
(1) Very independent: does not need much help at all
(2) Independent: need some help now and then
(3) Somewhat independent: it varies/depends on the problem
(4) Dependent: needs a lot of help
(5) Very dependent: needs constant help
APPENDIX E: SIBLING INVOLVEMENT AND CONTACT

The following section contains questions about your contact with your ill sibling. Please indicate the response that best answers each question.

1. Are you the primary caregiver, or the family member who feels most responsible for making sure your sibling is managing his/her illness?
   (1) Yes
   (2) No, who is: ______________ (e.g. mother, father, older sister, older brother, younger sister, grandparent, etc.)

2. How often do you speak with your ill sibling on the telephone?
   (1) At least once a day
   (2) At least once a week
   (3) At least once a month
   (4) At least once a year
   (5) Not at all in the past year
   (6) Not at all in the past year

3. How often do you visit with or have face-to-face contact with your ill sibling?
   (1) We live together (daily)
   (2) At least once a day
   (3) At least once a week
   (4) At least once a month
   (5) At least once a year
   (6) Not at all in the past year

4. In general, would you like more contact, less contact, or the same amount of contact with your ill sibling as you have now?
   (1) more contact
   (2) less contact
   (3) the same amount of contact

5. How involved do you feel you are in the life of your ill brother/sister?
   (1) not involved
   (2) a little involved
   (3) somewhat involved
   (4) very involved

6. How much responsibility would you say you have for taking care of your ill sibling?
   (1) no responsibility
   (2) a little responsibility
   (3) a moderate amount of responsibility
   (4) a great deal of responsibility

7. How would you rate your ability to be involved with your ill sibling based on your time availability?
   (1) poor
   (2) adequate
   (3) good
   (4) excellent
8. How would you rate your ability to be involved with your ill sibling (e.g., providing assistance/care-giving) based on your financial resources?
   (1) poor
   (2) adequate
   (3) good
   (4) excellent

9. At this point in your life, how much of your energy do you believe should be spent focusing on your own life/needs?
   (1) None of my energy
   (2) A little of my energy
   (3) A moderate amount of my energy
   (4) A lot of my energy
   (5) All of my energy
APPENDIX F: CURRENT CAREGIVING SCALE (CCS)

The following section asks you to think about how much help you may or may not provide to your ill sibling in certain areas. Please think about how much you have assisted your ill sibling in the past year.

1 = none
2 = seldom
3 = sometimes
4 = frequently

In the past year. I have assisted my ill sibling with:

1. household tasks like cleaning laundry, preparing meals, etc.
2. rides or assistance with transportation
3. shopping for groceries, clothes, and other basic needs
4. give money, or help to manage financial matters
5. emotional support or talking to him/her about personal problems
6. helping when he/she was sick or in crisis
7. helping by giving him/her gifts or presents
8. helping him/her deal with the symptoms of the illness
9. coordinating family visits or taking him/her out
10. arranging for needed services (such as dental or doctors, act as liaison with medical personnel or other professionals)
APPENDIX G: INTENTION TO CARE SCALE (ICS)

Listed below are a number of statements concerning whether you intend or expect to help your brother/sister in certain areas of his/her life at some point in the future. If you are currently helping your ill sibling in these areas, and intend to continue doing so in the future, please answer accordingly. Please read each statement carefully and indicate the extent to which you agree or disagree with each statement.

1 = strongly agree
2 = agree
3 = neutral
4 = disagree
5 = strongly disagree

1. I intend/expect to help my sibling with emotional support sometime in the future.

2. I intend/expect to help my sibling with basic needs (e.g., household tasks, shopping, transportation, etc.) sometime in the future.

3. I intend/expect to help my sibling with financial assistance sometime in the future.

4. I intend/expect to help my sibling with symptom management sometime in the future.

5. I intend/expect to help my sibling by arranging for supportive services sometime in the future.
APPENDIX H: POSITIVE REINTERPRETATION AND GROWTH SUBSCALE (PRGS)
AND EMOTIONAL PROCESSING SUBSCALE (EPS)

These questions deal with ways of coping with and making meaning of the experience of having a brother or sister with mental illness. Using the rating scale below please indicate how much you usually do these things to help you cope with your brother or sister’s mental illness.

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

1. I try to grow as a person as a result of the experience.
2. I realize that my feelings are valid and important.
3. I look for something good in what is happening.
4. I acknowledge my feelings.
5. I try to see it in a different light, to make it seem more positive.
6. I take time to figure out what I am really feeling.
7. I delve into my feelings to get a thorough understanding of them.
8. I learn something from the experience.

PRGS: Items 1, 3, 5, 8
EPS: Items 2, 4, 6, 7
APPENDIX I: PERSONAL LOSS – SIBLING VERSION (PLMI-S)

These questions deal with losses that some people who have a sibling with mental illness say that they sometimes feel. Please read each statement and indicate how much you agree with the statement using the rating scale below. There are no “right” or “wrong” answers.

1 = Strongly disagree  
2 = Somewhat disagree  
3 = Neither agree nor disagree  
4 = Somewhat agree  
5 = Strongly agree

1. Having a sibling with a mental illness has really changed who I am.  
2. I miss the kinds of friends that I had before my sibling became ill.  
3. I don’t plan for the future, but I do have hopes about what I’d like to see happen.  
4. I worry that having to provide assistance to my ill sibling might prevent me from getting or keeping a good job.  
5. On account of my sibling’s illness and his/her needs for support from me, I doubt that I will have the same kind of future as other people my age.  
6. People who knew my sibling before the illness would hardly recognize my sibling now.  
7. Because of my sibling’s illness, the plans I make for each day sometimes do not get done.  
8. I have lost friends because of my sibling’s mental illness.  
9. I miss the way my sibling used to be before he/she became ill.  
10. My future is as bright now as it was before my sibling became ill.  
11. Chances are very good that my sibling will get married and have a family of his or her own.  
12. I don’t enjoy being around people who have a mental illness.  
13. Since the illness, my sibling will probably never be able to own a home.  
14. My sibling’s mental illness has taken away much of my normal daily routine.  
15. I feel that I don’t have the kind of friends that other people my age have.
16. Since my sibling’s illness, I know that my plans for the future might be interrupted.

17. There are fewer things that I like doing since my sibling’s illness.

18. I haven’t really changed much because of my sibling’s mental illness.

19. Since my sibling’s illness, it’s harder for me to attend to other roles in my life like my job, or other family relationships.

20. My sibling’s mental illness has stopped me from being an important member of the family.
APPENDIX J: STRESS RELATED GROWTH SCALE-SHORT FORM (SRGS-SF)

Please answer the following questions with regard to your experiences with your sibling with a mental illness.

0=Not at all  
1=Somewhat  
2=A great deal

Because of my experiences with my ill sibling…

1. I learned to be nicer to others  
2. I feel freer to make my own decisions  
3. I learned that I have something of value to teach others about life  
4. I learned to be myself and not try to be what others want me to be  
5. I learned to work through problems and not just give up  
6. I learned to find more meaning in life  
7. I learned how to reach out and help others  
8. I learned to be a more confident person  
9. I learned to listen more carefully when others talk to me  
10. I learned to be open to new information and ideas  
11. I learned to communicate more honestly with others  
12. I learned that I want to have some impact on the world  
13. I learned that it is okay to ask others for help  
14. I learned to stand up for my personal rights  
15. I learned that there are more people who care about me than I thought
APPENDIX K: MEANING

1 = not at all
2 = sometimes
3 = often
4 = very often

1. Overall, *how much* have you been *trying to* make sense of or find any meaning in the experience of having a brother or sister with a mental illness?

2) Overall, how *successful* have you been in actually making sense of or finding meaning in the experience of having a brother or sister with a mental illness? (i.e., have you actually gained or made meaning out of the experience?)

3) When you think about having a brother or sister who has a serious mental illness, how much does it make you think that the world *is NOT* fair or just?
APPENDIX L: PERSONAL GAINS (PG)

1. Briefly describe any kinds of personal gains that you feel as a result of having a sibling with a mental illness?
APPENDIX M: SELF AND SIBLING CARE AND COMMITMENT (SSCC)

*When it comes to having a sibling with mental illness, some adults tell us that they often have to make decisions about when to take care of themselves and when to be involved with their ill sibling or other family members. Some people talk about how they have to take care of their own personal needs, such as their own mental health, career, or spouse/kids. Other people talk about how they are committed to taking care of the needs of their ill sibling. For each item, please use the following scale to indicate how much you agree or disagree with each statement.*

1 = strongly disagree  
2 = disagree  
3 = neither agree nor disagree  
4 = agree  
5 = strongly agree

1. I feel "torn" about how much I should personally sacrifice when it comes to meeting the needs of my ill sibling.

2. I don't have the time or energy to do things for my ill sibling anymore.

3. I do the best that I can to pay attention to my own concerns as well as the concerns of my ill sibling.

4. I put my ill sibling's needs before my own needs.

5. At this point in my life, I am focusing on my own welfare/needs.

6. I strive to find a balance between doing things for myself and doing things for my ill sibling.

7. I take the time to assist my ill sibling when s/he needs it.

8. I do not have any problems deciding between caring for my ill sibling and caring for myself.

9. I feel "caught in the middle" between doing things for myself versus doing things for my ill sibling.

10. I make it a point to spend time attending to both my own welfare and the welfare of my ill sibling.

11. I distance myself from my ill sibling so that I won't get too physically or emotionally drained.

12. I have difficulty deciding when I should or should not do things for my ill sibling.
13. I focus on myself and my own welfare/needs first, and then worry about the needs of my ill sibling.

14. I do not "set limits" or say "no" when my ill sibling needs something from me.

15. I place equal importance on my own needs and the needs of my ill sibling.

16. I feel like it is my family duty to be involved with my ill sibling.
Table 1

**Participant Characteristics**

<table>
<thead>
<tr>
<th>N = 103</th>
<th>Number (%)</th>
<th>Number (%)</th>
</tr>
</thead>
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<td>Gender*</td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (21.4)</td>
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</tr>
<tr>
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<td>Married/ Remarried</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Divorced/ Separated/ Widow</td>
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<td>Education</td>
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<td>Both NAMI and FSG</td>
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</tr>
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<tr>
<td>Other</td>
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*Note.* * Indicates missing data for two or more individuals
Table 2

*Reported Characteristics of Ill Sibling*

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<tr>
<td>Living with Partner</td>
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</tr>
<tr>
<td>Married/Remarried</td>
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</tr>
<tr>
<td>Divorced/Separated/Widow</td>
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<tr>
<td><strong>Primary Caregiver</strong></td>
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<td>Parent</td>
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<tr>
<td>Well-Sibling (Participant)</td>
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<tr>
<td>Other Family Member</td>
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</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full Time</td>
<td>8 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Part Time</td>
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<tr>
<td>Retired</td>
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<tr>
<td>Disabled</td>
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<tr>
<td><strong>Financial Situation</strong></td>
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<tr>
<td>Just enough money</td>
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<tr>
<td>A little money left over</td>
<td>15 (14.6)</td>
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<tr>
<td>More than enough money</td>
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<tr>
<td><strong>Education</strong></td>
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<td>Home With Formal Supervision</td>
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<td>Correctional Facility</td>
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<td>Bipolar</td>
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<td>Personality Disorder</td>
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</tr>
<tr>
<td>Don’t Know</td>
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<td></td>
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<tr>
<td><strong>Length of Diagnosis</strong></td>
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<td></td>
</tr>
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<td>1-3 years</td>
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<td>3-5 years</td>
<td>17 (16.5)</td>
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<td>5-10 years</td>
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<td>10-20 years</td>
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<tr>
<td>More than 20 years</td>
<td>24 (23.3)</td>
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</tr>
</tbody>
</table>

*Note.* * Indicates missing data for two or more individual
Table 3
Zero-Order Correlations Matrix for Research Measures and Demographic Variables

| Variables          | M   | SD  | 1     | 2     | 3     | 4     | 5     | 6     | 7     | 8     | 9     | 10    | 11    | 12    | 13    | 14    | 15    | 16    | 17    | 18    |
|--------------------|-----|-----|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| CCS                | 2.16| .80 | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| ICS                | 3.68| 1.06| .51   | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| SRGS               | 1.15| .56 | .14   | .08   | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| SSCM-Amb           | 3.13| .99 | .49   | .46   | .02   | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| SSCM-Self          | 3.34| .79 | -.57  | -.43  | -.10  | -.29  | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| SSCM-Bal           | 3.43| .82 | .47   | .43   | .27   | .34   | -.54  | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| PLMI-S             | 2.85| .69 | .37   | .17   | .04   | .54   | -.18  | .09   | --    |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
| EPS                | 2.75| .88 | -.15  | -.15  | .18   | -.24  | .07   | .03   | -.15  | --    |       |       |       |       |       |       |       |       |       |       |       |       |
| PRG                | 2.89| .84 | .10   | .11   | .40   | .01   | -.10  | .29   | .00   | .52   | --    |       |       |       |       |       |       |       |       |       |       |       |       |
| Gender             | .79 | .41 | .03   | -.06  | .17   | .03   | .15   | -.15  | .24*  | .04   | .12   | --    |       |       |       |       |       |       |       |       |       |       |       |
| S.Grp Affil.       | .27 | .45 | .17   | .02   | .15   | .09   | -.16  | .16   | .23*  | .00   | .04   | .11   | --    |       |       |       |       |       |       |       |       |       |       |
| S.Grp Affil.       | .11 | .31 | .20*  | .17   | .31   | .03   | -.06  | .15   | -.08  | .13   | .29   | .03   | -.21* | --    |       |       |       |       |       |       |       |       |       |
| Age                | 38.9| 13.8| .27   | .16   | .12   | .06   | -.32  | .12   | .06   | .05   | .08   | .04   | .18   | .18   | --    |       |       |       |       |       |       |       |       |
| Severity           | 3.17| .80 | .13   | .15   | -.08  | .20*  | .06   | -.09  | .38   | -.17  | -.21* | .06   | -.03  | -.24*  | -.15  | --    |       |       |       |       |       |       |       |
| Dependence         | 3.32| 1.07| .28   | -.07  | .20*  | .03   | -.06  | .35   | -.28  | -.07  | .02   | .04   | -.08  | -.23*  | .44   | --    |       |       |       |       |       |       |       |
| Finan. Constr      | 3.13| .96 | -.28  | -.01  | -.01  | -.20* | .19   | -.04  | -.17  | -.09  | .03   | -.08  | -.06  | -.18  | -.32  | -.04  | -.04  | --    |       |       |       |       |       |       |
| Time Constr        | 2.91| 1.04| -.34  | -.01  | -.14  | -.12  | .37   | -.13  | -.09  | -.14  | -.12  | .07   | .24*  | -.06  | .26   | -.01  | .09   | .47   | --    |       |       |       |       |
| Pers Constr        | 3.72| .71 | -.20  | -.20  | .01   | -.16  | .35   | -.20* | -.08  | -.03  | .01   | .16   | -.10  | -.04  | -.11  | -.09  | -.09  | .19   | .07   | --    |       |       |       |

Note. Correlations with * have a p<.05. Correlations in boldface have a p<.01.

a Support group affiliation dummy coded to compare no affiliation to affiliation in either NAMI or another support group
b Support group affiliation dummy coded to compare no affiliation to affiliation in both NAMI and another support group

Note: CCS = Current Caregiving Scale; ICS = Intention to Care Scale; SRGS = Stress-Related Growth Scale; SSCM-Amb. = Self and Sibling Care Measure – Ambivalence Subscale; SSCM-Self = Self and Sibling Care Measure – Self Focus Subscale; SSCM-Bal = Self and Sibling Care Measure – Balance Subscale; PLMI-S = Personal Loss due to Mental Illness – Sibling Version; EPS = Emotional Processing Subscale; PRG = Positive Reappraisal and Growth Subscale; Gender = Gender of Participant; S. Grp. Affil. = Support Group Affiliation; Age = Participant Age; Severity = Participant Illness Severity Level; Dependence = Participant Dependence Level; Financial C. = Financial Constraint; Time C. = Time Contraints; Personal C. = Personal Constraints.
Table 4

Hierarchical Regressions of Current Caregiving and Intentions to Care

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<th>Criterion Variable</th>
<th>Predictor variables</th>
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<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
<th>$R^2$</th>
<th>Adj $R^2$</th>
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<td>.12**</td>
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<td>-03</td>
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<td>-09</td>
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<td></td>
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<td>.20*</td>
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<td>2. Severity</td>
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<td>.09</td>
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<td>.01</td>
<td>.25</td>
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<tr>
<td></td>
<td>3. Emotional Processing</td>
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<td>-.15</td>
<td>-.11</td>
<td>.27</td>
<td>.21</td>
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<td></td>
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<tr>
<td></td>
<td>Positive Reappraisals</td>
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<td>.08</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Personal Loss</td>
<td>.06**</td>
<td>-.01</td>
<td>.30**</td>
<td>.33</td>
<td>.26</td>
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</table>

| Intention to Care  | 1. Gender,          | .03       | -.06   | -.08   | -.10   | -.12   | .03   | .01       | .19 |
|                    | Age,                |           |        |        |        |        |       |           |     |
|                    | Support Group Affiliation$^a$ | .05       | .08    | .07    | .05    |        |       |           |     |
|                    | Support Group Affiliation$^b$ | .17       | .22*   | .19    | .18    |        |       |           |     |
|                    | 2. Severity         | .05       | .20    | .23*   | .18    | .08    | .02   |           |     |
|                    | Dependence          |           |        |        |        |        |       |           |     |
|                    | 3. Emotional Processing | .05       | -.24*  | -.22   | .13    | .05   |       |           |     |
|                    | Positive Reappraisals |           | .22    | .20    |        |       |       |           |     |
|                    | 4. Personal Loss    | .02       | .17    | .14    | .06    |       |       |           |     |

Note. * $p < .05$, ** $p < .01$.

$^a$As a categorical variable with three groups, support group affiliation was dummy-coded across two variables, with the largest group, no affiliation, serving as the reference group. $^b$The second of the two dummy coded variables for support group affiliation.
Table 5

Hierarchical Regression of Stress-Related Personal Growth

<table>
<thead>
<tr>
<th>Criterion Variable</th>
<th>Predictor variables</th>
<th>$R^2$</th>
<th>Change</th>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
<th>$R^2$</th>
<th>Adj $R^2$</th>
<th>R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress-Related Personal Growth</td>
<td>Gender, Support Group Affiliation*</td>
<td>.15**</td>
<td>.12</td>
<td>.13</td>
<td>.13</td>
<td>.10</td>
<td>.10</td>
<td>.15</td>
<td>.12</td>
<td>.39**</td>
</tr>
<tr>
<td></td>
<td>Age, Dependence</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Support Group Affiliation*</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Support Group Affiliation b</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional Processing, Positive Reappraisals</td>
<td>.08*</td>
<td>.17</td>
<td>.08</td>
<td>.08</td>
<td>.16</td>
<td>.10</td>
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<tr>
<td></td>
<td>Personal Loss</td>
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<td></td>
<td></td>
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</tr>
</tbody>
</table>

Note.  * $p < .05$, ** $p < .01$.

*aAs a categorical variable with three groups, support group affiliation was dummy-coded across two variables, with the largest group, no affiliation, serving as the reference group. *bThe second of the two dummy coded variables for support group affiliation.
### Table 6
Hierarchical Regressions of Self and Sibling Care Subscales

<table>
<thead>
<tr>
<th>Criterion Variable</th>
<th>Predictor variables</th>
<th>$R^2$ Chg</th>
<th>$B$</th>
<th>$R^2$</th>
<th>Adj $R^2$</th>
<th>R</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Step 1</td>
<td>Step 2</td>
<td>Step 3</td>
<td>Step 4</td>
<td></td>
</tr>
<tr>
<td>SSCM-Balance</td>
<td>1. Gender, Age, Support Group Affiliation$^a$ Support Group Affiliation$^b$</td>
<td>0.09</td>
<td>-0.17</td>
<td>-0.46</td>
<td>0.02</td>
<td>0.05</td>
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<tr>
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<td>2. Severity Dependence</td>
<td>0.00</td>
<td>-0.02</td>
<td>0.04</td>
<td>0.03</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td>3. Emotional Processing Positive Reappraisals</td>
<td>0.08*</td>
<td>-0.16</td>
<td>0.13</td>
<td>0.16</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td>4. Personal Loss</td>
<td>0.02</td>
<td>0.19</td>
<td>0.19</td>
<td>0.11</td>
<td>0.11</td>
</tr>
<tr>
<td>SSCM-Ambivalence</td>
<td>1. Gender, Age, Support Group Affiliation$^a$ Support Group Affiliation$^b$</td>
<td>0.01</td>
<td>0.05</td>
<td>0.03</td>
<td>0.02</td>
<td>0.01</td>
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<tr>
<td></td>
<td>2. Severity Dependence</td>
<td>0.07*</td>
<td>0.17</td>
<td>0.19</td>
<td>0.01</td>
<td>0.08</td>
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<tr>
<td></td>
<td>3. Emotional Processing Positive Reappraisals</td>
<td>0.04</td>
<td>-0.24</td>
<td>-0.14</td>
<td>0.12</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td>4. Personal Loss</td>
<td>0.27**</td>
<td>0.63**</td>
<td>0.39</td>
<td>0.33</td>
<td>0.39**</td>
</tr>
<tr>
<td>SSCM-Self-Focus</td>
<td>1. Gender, Age, Support Group Affiliation$^a$ Support Group Affiliation$^b$</td>
<td>0.15**</td>
<td>-0.30**</td>
<td>-0.32**</td>
<td>-0.31**</td>
<td>-0.29**</td>
</tr>
<tr>
<td></td>
<td>2. Severity Dependence</td>
<td>0.00</td>
<td>0.00</td>
<td>0.03</td>
<td>0.05</td>
<td>0.16</td>
</tr>
<tr>
<td></td>
<td>3. Emotional Processing Positive Reappraisals</td>
<td>0.03</td>
<td>0.17</td>
<td>0.13</td>
<td>0.18</td>
<td>0.11</td>
</tr>
<tr>
<td></td>
<td>4. Personal Loss</td>
<td>0.04*</td>
<td>-0.23*</td>
<td>0.22</td>
<td>0.14</td>
<td>0.14</td>
</tr>
</tbody>
</table>

**Note.** *p < .05, **p < .01.*

$^a$As a categorical variable with three groups, support group affiliation was dummy-coded across two variables, with the largest group, no affiliation, serving as the reference group. $^b$The second of the two dummy coded variables for support group affiliation.